

THE EXPERIENCE OF POST-CRANIOTOMY PAIN AMONG PERSONS WITH BRAIN  
TUMORS

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Submitted to the faculty of the University Graduate School  
in partial fulfillment of the requirements  
for the degree  
Doctor of Philosophy  
in the School of Nursing,  
Indiana University

July 2018

Accepted by the Graduate Faculty of Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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## **DEDICATION**

I dedicate this work to all of my family who have supported and encouraged me throughout this long journey: To my father, James D. Foust, who showed me academia firsthand, allowed me to tag along to all of the classes he taught, and showed me women can be anything they want to be; to my mother, Carolyn Pugh Foust who helped to break the glass ceiling and showed me how successful one can be despite life's setbacks; to my sister, Sheryl Foust Morgan, who earned her doctorate and pushed me along even when I doubted myself; to my brother, Bill Foust, who has always stood by his little sister and is arguably the most successful of any of us; and last but not least, to my wonderful sons, Benjamin Helton and Brennan Guilkey. You boys are a continual inspiration to me. I hope you two know that you are the best things that have ever happened to me and that everything I've ever done has been for you. I love you.

Thank you also to all of the other family and friends who have helped me along the way. There will never be enough room to thank you all, and for that, I am fortunate.

## **ACKNOWLEDGEMENTS**

Thank you to my mentor and dissertation chair, Diane Von Ah, for your continual encouragement and support, even when research, classes, grants, and life became difficult. You taught me that I could research something I knew a little about already (!) and were a continual cheerleader, championing me in the research, academic, and personal arenas. I am so blessed to have had you as an advisor and as a supervisor. You showed me how to be persistent but also to relax and laugh at myself. Thank you to Barbara Habermann – without you, I could not have gotten my start and I never would have met Diane. Thank you to Claire B. Draucker, who worked tirelessly with me and who pushed me beyond what I thought I was capable of. This project would never have been completed without your continual support and encouragement. Thank you also to the other members of my research committee – Janet S. Carpenter, Kurt Kroenke, and Cynthia Stone – for allowing me to perform secondary analyses on their data, for sticking by me when the resulting work took far longer than anticipated, and for their countless suggestions, pointers, and edits, all of which have served to make my work far better than it would have been without their input.

Thank you also for those who have undergone craniotomies for the treatment of brain cancer and for those suffering from undertreated pain. Without you, this research never would have been possible.

Data for this study were collected under a Sigma Theta Tau International Honor Society of Nursing Research Grant (Guilkey PI). Its content is solely the responsibility of the authors and does not necessarily represent the views of Sigma Theta Tau International.

The study PI (Guilkey) was supported by the National Institutes of Health/National Institute of Nursing Research Scholars Training for the Advancement of Research (STAR) T32 grant award number T32NR007066, the Jonas Center for Nursing Excellence Leadership Fellowship, and the Indiana University School of Nursing Research Incentive Fund. Its content is solely the responsibility of the authors and does not necessarily represent the views of the National Institutes of Health, the Jonas Center for Nursing Excellence, or the Indiana University School of Nursing.

Rebecca Elizabeth Foust

## THE EXPERIENCE OF POST-CRANIOTOMY PAIN AMONG PERSONS WITH BRAIN TUMORS

Post-craniotomy brain tumor patients often experience pain in the post-surgical period which can negatively affect recovery and surgical outcomes. Research with this population has focused on pharmacological treatments of post-craniotomy pain and measurement of pain intensity. Little is known about how these patients experience the quality of their pain and how this pain is managed. The purpose of this dissertation was to provide an in-depth description of the experience of post-craniotomy pain during the post-surgical period. The information gained about how post-craniotomy patients experience pain and pain management will contribute the development of effective, tailored interventions to enhance patient satisfaction and outcomes. This dissertation project was composed of two components. The first component was an integrative review of literature examining the evidence of pain and associated symptoms in adult (aged 21 and older), post-craniotomy brain tumor patients. The review examined studies from the past fourteen years that focused on the incidence and treatment of post-craniotomy pain. It revealed that the majority of post-craniotomy patients experience moderate to severe pain after surgery. This pain is associated with nausea, vomiting, changes in blood pressure, and increased length of hospital stay. The second component was a qualitative descriptive study of a sample of 28 adult (aged 21 and older) post-craniotomy patients hospitalized on an inpatient neurosurgical stepdown unit at a Midwestern urban teaching hospital. During semi-structured interviews, participants described their experiences of post-craniotomy pain and of their experiences of post-craniotomy pain management. Data generated from the qualitative descriptive study were analyzed and resulted in two qualitatively derived products. The first was a description of participants' experiences of the quality of their post-craniotomy pain during

the post-surgical period. The six types of pain quality described were *pain as pressure*, *pain as tender or sore*, *pain as stabbing*, *pain as throbbing*, *pain as jarring*, and *pain as itching*. The second was a description of how post-craniotomy patients experience the management of their pain during the post-surgical period. The four groups of types of pain management experiences described were *pain-as-non-salient, routine pain management*; *pain-as-non-salient, complex pain management*; *pain-as-salient, routine pain management*; and *pain-as-salient, complex pain management*.

Diane M. Von Ah, Ph.D., RN, FAAN, Chair

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## **CHAPTER ONE**

Chapter 1 introduces the dissertation project on pain in the post-craniotomy brain tumor patient. The dissertation includes an integrative review of the literature and a qualitative descriptive study. This chapter provides a discussion of the significance of the topic, describes the purpose and specific aims of the dissertation, discusses the theoretical basis for this work, defines concepts that will be used throughout, and outlines study methods and limitations. In addition, this chapter will introduce Chapters 2 through 5.

### **Significance and Background**

#### **Brain Tumors**

Brain tumors are masses of cells whose replication is unregulated, resulting in abnormal growths within the brain.<sup>1</sup> Approximately 85-90% of central nervous system tumors are brain tumors.<sup>2</sup> The incidence of primary malignant brain tumors worldwide is 3.4 per 100,000 persons.<sup>3</sup> In the United States, the incidence of malignant and benign primary brain tumors is 22.64 per 100,000 persons with over 375,000 new cases of primary and metastatic brain tumor diagnosed per year.<sup>3</sup> In 2017, it was estimated that over 80,000 new cases of primary brain tumor were diagnosed of which over 23,000 were malignant.<sup>4,5</sup> Approximately 700,000 people in the United States are currently living with brain tumors.<sup>6,7</sup> Survival rates vary significantly by tumor type,<sup>4,6</sup> with increasing age associated with lower survival rates.<sup>4</sup> Average five-year survival rates range from as low as 5% for a 55-64 year-old patient diagnosed with a glioblastoma to as high as 92% for a 20-44 year-old patient diagnosed with an ependyoma.<sup>4</sup> Average five-year survival rates for all types of malignant brain tumor are slightly over 30%.<sup>8</sup>

Tumors originating in the brain are classified as primary brain tumors, whereas those originating elsewhere in the body are classified as metastatic brain tumors.<sup>9</sup> As with other types of tumors, brain tumors can be benign or malignant, although unlike

other types of tumors, brain tumors rarely spread to other areas of the body and are more likely to spread within the brain tissue itself.<sup>1</sup> Based on the appearance of the cells underneath a microscope, brain tumor severity is classified as Grade I-IV according to World Health Organization (WHO) guidelines. Grade I tumors are the least invasive and require less aggressive treatment, and Grade IV tumors are the fastest-growing and most invasive and require more aggressive treatment.<sup>9,10</sup> Brain tumors are also classified based on the location of origin.<sup>9,11</sup> Although brain tumors commonly arise from glial cells, which are cells that support the brain's nerve cells, tumors can also originate in the meninges and in other areas of the brain such as the hypothalamus.<sup>1</sup> The most common types of brain tumors are gliomas, with astrocytomas, oligodendrogliomas, and ependyomas being less common.<sup>9,11</sup> Other types of brain tumors include meningiomas, medullablastomas, gangliomas, and schwannomas.<sup>9,11</sup>

The symptoms associated with brain tumors vary with the location of the tumor.<sup>1,7</sup> For example, tumors located in the cerebellum can cause poor coordination and imprecise movement of limbs, tumors in the brain stem can affect breathing and heartbeat, and tumors in cranial nerves can cause problems with vision, swallowing, or hearing.<sup>1</sup> Headache, seizures, cognitive changes, and mood swings are symptoms frequently associated with brain tumors.<sup>7</sup>

### **Craniotomies**

Craniotomies are the removal of a section of bone in order to access the brain.<sup>12</sup> They are the most common treatment for brain tumor, regardless of tumor type.<sup>12</sup> The section of skull bone is removed using specialized tools and replaced after surgery.<sup>12</sup> Craniotomies can be performed with computerized guidance and concurrent imaging, which can enable better identification of tumor versus non-tumor tissue.<sup>12</sup> Craniotomies allow the surgeon to establish an accurate diagnosis and to remove as much of the tumor as possible<sup>13</sup> and may be followed with chemotherapy and/or radiation.<sup>14</sup>

Craniotomies are classified according to where on the head they are performed.<sup>12</sup> For example, bifrontal craniotomies expose the forehead through an incision behind the hairline.<sup>12</sup> These types of craniotomies allow the surgeon to remove more bone and manipulate less brain tissue and are frequently used for tumors that are inoperable using other techniques.<sup>12</sup> Retro-sigmoid craniotomies allow for visualization of the skull base through an incision behind the ear allowing access to the cerebellum and brainstem and are frequently used for removal of meningiomas and vestibular schwannomas.<sup>12</sup>

### **Post-craniotomy Pain**

Brain tumor patients who have had craniotomies are assumed to experience little post-surgical pain because there are few pain receptors in brain tissue.<sup>15</sup> Yet upwards of 60% of post-craniotomy patients experience moderate to severe pain after surgery.<sup>15-17</sup> Post-craniotomy pain can result from surgical incisions, muscle retraction and reflection, and irritation of the meninges.<sup>15</sup> Greater intensity of post-craniotomy pain is related to greater tissue damage during surgery.<sup>15</sup> Post-craniotomy pain has been described as similar to that of a tension headache and can be unremitting.<sup>15,18</sup> Post-craniotomy pain varies according to the surgical site, with frontal craniotomies being associated with less pain than those performed at the skull base.<sup>15</sup>

Post-craniotomy pain in alert and oriented patients is primarily assessed using numerical pain ratings, such as visual analogue scales, numerical rating scales or visual numeric scales.<sup>15</sup> A recent review of 26 studies of treatment for post-craniotomy pain revealed that all of the studies used one-dimensional numerical ratings to assess pain intensity and did not measure other aspects of pain such as timing, distress, affect, and quality.<sup>16</sup> If post-craniotomy patients cannot describe their pain after surgery, provider observation of behavior may be necessary to assess pain.<sup>15</sup>

## **Treatments for Post-Craniotomy Pain**

Treatment for post-craniotomy pain includes a variety of pharmacologic interventions, although most have limitations. Local anesthetics, such as scalp blocks, decrease post-craniotomy pain but wear off quickly.<sup>15,18</sup> Parenteral and/or enteral opioids are commonly used to control post-craniotomy pain but have a number of adverse effects including sedation, respiratory depression, and neurological changes.<sup>17-21</sup> Other pharmacologic interventions to control post-craniotomy pain include the use of nonopioid analgesics such as paracetamol and COX-2 inhibitors and antiepileptics such as gabapentin.<sup>15,18</sup> The American Pain Society considers nonpharmacological interventions such as acupuncture, massage, and cold or heat therapy to be safe for pain management, although few studies have examined the efficacy of these interventions in the post-craniotomy pain population.<sup>22</sup>

## **Outcomes of Untreated Post-Craniotomy Pain**

Uncontrolled post-craniotomy pain is associated with increased anxiety and depression,<sup>23</sup> increased intracranial pressure and blood pressure,<sup>15,17,18,24</sup> nausea, vomiting, and restlessness.<sup>17,24</sup> The development of such side effects contributes to compromised neurological examination<sup>15,17</sup> and prolonged hospital stay.<sup>25,26</sup> Post-craniotomy pain is also associated with decreased patient satisfaction,<sup>27,28</sup> increased healthcare costs,<sup>18,26</sup> increased disability, decreased quality of life, and increased mortality.<sup>17</sup> Poorly managed post-craniotomy pain can result in the development of persistent pain due to changes in neurological sensitivity precipitated by nerve injury.<sup>29,30</sup>

## **Need for Further Research**

Pain is a complex symptom that is comprised of multiple dimensions including intensity, duration, affect, quality, and location.<sup>31,32,33</sup> Most research on post-craniotomy pain, however, has focused on the efficacy of pharmacological treatments.<sup>16</sup> Therefore, despite the prevalence and negative outcomes associated with post-craniotomy pain,<sup>29</sup>

little is known about the experience of post-craniotomy pain from the perspectives of patients.<sup>34</sup> To improve pain care in this population, information about how patients experience the quality of their pain and how they view their pain management experiences is needed.

### **Purpose and Aims**

The purpose of this project was to provide an in-depth description of the experience of post-craniotomy pain during the post-surgical period. The specific aims were as follows:

**Aim 1:** To conduct an integrative literature review to examine the evidence of pain and associated symptoms in adult, post-craniotomy brain tumor patients hospitalized on intensive care units (Chapter One).

**Aim 2:** To describe how persons who have undergone a craniotomy for the excision and removal of a brain tumor describe the quality of their pain during the post-surgical period (Chapter Two).

**Aim 3:** To describe how persons who have undergone a craniotomy for the excision and removal of a brain tumor experience pain management during the post-surgical period (Chapter 3).

### **Theoretical Perspective**

The Theory of Unpleasant Symptoms (TOUS) was used as a theoretical basis for this dissertation project. While some theories, such as the University of Minnesota's Symptom Experience in Time (SET),<sup>35</sup> the Symptoms Experience Model (SEM),<sup>36</sup> and the Theory of Symptom Management (TSM), have addressed overall symptom experiences,<sup>37,38</sup> and some theories, such as the Gate Control Theory<sup>39,40</sup> and the Neuromatrix Theory, have addressed pain more specifically,<sup>41</sup> the TOUS provides the foundation for this project because it considers symptom experiences, including pain, through a broad lens.

While much of the research on post-craniotomy pain focuses on the intensity of the pain and pharmacological treatments, I was interested in the overall experience of post-craniotomy pain including its quality and how it is managed in the post-surgical period. Therefore the TOUS was chosen to underpin this dissertation because it addresses several aspects of the symptom experience<sup>42</sup> and has been used to study symptoms in various populations,<sup>43-46</sup> including patients with cancer.<sup>42</sup> Because the TOUS addresses symptoms in a comprehensive way, it makes it an ideal foundation for a project seeking an in-depth description of the experience of post-craniotomy pain from the patient's perspective.

The TOUS was first purposed by Elizabeth Lenz in 1995.<sup>47</sup> The theory posits that symptoms occur alone or in conjunction with other symptoms and when symptoms are experienced simultaneously, they have the potential to catalyze each other. If one symptom is alleviated, therefore, it is possible that other symptoms would be eased as well.<sup>42</sup> This effect has been shown in studies in which the treatment of pain resulted in decreased depression and/or anxiety.<sup>48-51</sup> The TOUS also asserts that symptoms can either be caused by a single event or can develop over time.<sup>42</sup>

According to the TOUS, three reciprocal components affect the symptom experience: 1) the symptom itself; 2) the influencing factors that either cause or affect the nature of the symptom; and 3) the consequences of the symptom.<sup>42</sup> Influencing factors can be physiological, psychological, or situational.<sup>42</sup> Physiological factors can include the patient's age, developmental stage, and comorbidities associated with the illness.<sup>42</sup> Psychological factors can include a person's emotional state, perceived level of self-efficacy, felt uncertainty associated with the illness, and the meaning ascribed to the illness.<sup>42</sup> Situational factors can include a person's social support system, occupation, and family or work demands.<sup>42</sup> The influencing factors can interact with each other and with other symptoms to affect the experience of the symptom.<sup>42</sup> The consequences of



symptoms are the effects the symptom has on functional and/or cognitive performance.<sup>42</sup>

Functional performance is the ability to perform physical and mental tasks associated with the individual's role in society, and cognitive performance is the ability to reason, concentrate, and problem solve.<sup>42</sup> Thought patterns in particular are believed to influence the symptom experience.<sup>42</sup> The relationships among the symptoms, influencing factors, and consequences are considered to be reciprocal rather than linear.<sup>42</sup>

The TOUS describes four different dimensions of symptoms: 1) intensity, (i.e., severity), 2) timing, (i.e., duration or frequency), 3) distress (i.e., perceived bother), and 4) quality (i.e., how the symptom feels).<sup>42</sup> The four dimensions interact with each other to produce the overall experience of the symptom.<sup>42</sup> While these dimensions are all measurable, the dimension of quality can be difficult to assess and is often dependent on the patient's culture and language.<sup>42</sup> This dissertation focuses on the symptom of pain itself; the quality of pain, as described in this theory; and on the pain management experience, which can be an importing influencing factor.

### **Concepts and Definitions**

The following table displays the definitions of the major concepts that will be used throughout this dissertation project. The definitions are divided according to the concepts related to my substantive focus (post-craniotomy pain) and the methodological approaches used to answer the specific aims.

<b>Substantive Concepts</b>	
<b>Concept</b>	<b>Definition</b>
Pain	A subjective experience comprised of sensory and emotional elements, including mental annoyance, suffering,

	and/or distress. <sup>33,52-54</sup> The characteristics of pain include intensity, affect, quality, and location. <sup>32,55</sup> Pain is influenced by physiological, psychological, cultural and social factors. <sup>28,29</sup>
Pain intensity	The severity of pain typically measured with a numerical rating given by the patients indicating their present pain level. <sup>56</sup>
Pain affect	Impact of the pain on mood and enjoyment of life. <sup>57</sup>
Pain quality	How the pain feels, as described by the patient. For example, a patient may describe pain as burning, tingling, throbbing, dull, achy, etc. <sup>56</sup>
Pain duration	How long the pain has been experienced. Pain can be acute or persistent and can be consistent or intermittent. <sup>56</sup>
Pain location	Where the pain is located, which is of importance because many patients have pain at multiple sites. <sup>56</sup>
Pain management	Design of a comprehensive, multidisciplinary treatment plan to address pain. <sup>58</sup> Includes evaluating and diagnosing the pain, prescribing

	<p>medications and/or performing procedures such as blocks and injections to improve pain, and coordination of additional treatments such as physical therapy, psychological therapy, or rehabilitation.<sup>58</sup></p>
Numerical rating scale (NRS)	<p>A one-dimensional pain scale that asks the patient to rate the intensity of his or her pain from 0 to 10 or 0 to 100.<sup>59</sup> Higher numbers represent higher self-reported levels of pain.<sup>59</sup> The NRS correlates positively and significantly with other measures of pain intensity.<sup>59</sup></p>
Visual analogue scale (VAS)	<p>A one-dimensional pain scale consisting of a line with endpoints labeled “no pain” and “worst pain.”<sup>59</sup> Patients are asked to rate the intensity of their pain along the line.<sup>59</sup> The VAS correlates with other measures of pain intensity and with pain behaviors.<sup>59</sup></p>
Visual numeric scale (VNS)	<p>A one-dimensional pain scale consisting of a numeric scale with visual cues including bars of different heights and/or shades.<sup>60</sup> Patients are asked to rate the intensity of their pain along the scale.<sup>60</sup></p>

	The VNS correlates strongly with the VAS. <sup>60</sup>
Cancer	A group of related diseases where the body's cells divide without stopping and may spread into other surrounding tissues. <sup>61</sup> Cancer can begin anywhere in the body. <sup>61</sup> Cancer may form solid tumors, although cancers of the blood do not. <sup>61</sup>
Brain tumor	Masses of cells whose reproduction is unregulated, resulting in abnormal growths in the brain. <sup>62</sup>
Craniotomy	Removal of part of the skull, exposing the brain. The removed portion of skull is replaced after the brain surgery is completed. <sup>12</sup>
Supratentorial	The front of the brain, consisting of the cerebrum. <sup>63</sup> This region of the brain controls movement, vision, touch, hearing, judgment, reasoning, problem solving, memory, and emotions. <sup>63</sup>
Infratentorial	The back of the brain, consisting of the cerebellum. <sup>63</sup> This region of the brain coordinates muscle movements, balance, and equilibrium. <sup>63</sup>

Post-surgical period	The period immediately after surgery and typically extending throughout the hospital stay.
<b>Methodological Concepts</b>	
<b>Concept</b>	<b>Definition</b>
Integrative review	A review method that synthesizes literature, allowing for a comprehensive understanding of a phenomenon or healthcare problem. <sup>64</sup> Integrative reviews allow for inclusion of different methodologies such as experimental and non-experimental designs. <sup>64</sup>
Qualitative Description (QD)	A research method that allows the researcher to describe the experiences of persons who share common health challenges. <sup>65</sup> QD uses semi-structured interviews to generate data and describes the data in straight-forward terms using low-inference analytic strategies to generate surface descriptions of experiences. <sup>65</sup> QD is frequently used to answer pragmatic questions. <sup>65</sup>
Content analysis	A systematic way of analyzing and coding written texts, allowing for quantification of qualitative data. <sup>66</sup>

## Methods

The following section describes the methods used to meet the three specific aims. I conducted an integrative literature review for Aim 1<sup>67</sup> and a qualitative descriptive study for Aims 2 and 3.<sup>65</sup>

### Integrative Literature Review

An integrative literature review is a method used to summarize the findings of research studies that have been done on a given topic and that address the same or similar hypotheses.<sup>67</sup> In this project, the integrative review strategies described by Cooper<sup>67</sup> were used. Cooper outlines seven stages of an integrative review. The stages are 1) formulating the problem; 2) searching the literature; 3) gathering information from the studies; 4) evaluating the quality of the studies; 5) analyzing and integrating the outcomes of the studies; 6) interpreting the evidence; and 7) presenting the results.<sup>67</sup>

In the first stage, formulating the problem, the reviewer clearly identifies the hypotheses to be examined and conceptually and operationally defines the relevant variables.<sup>67</sup> The reviewer decides if the purpose of the review is to describe the variables or to examine the relationships among them.<sup>67</sup> In the second stage, searching the literature,<sup>67</sup> the reviewer selects the target population to allow generalization to that population.<sup>67</sup> The reviewer searches relevant data bases and complementary literature using pre-determined search terms to select the literature to be included in the review.<sup>67</sup> In the third stage, gathering information from the studies,<sup>67</sup> the reviewer extracts relevant information according to pre-determined procedures.<sup>67</sup> In the fourth stage, evaluating the quality of the studies,<sup>67</sup> the reviewer evaluates the relevancy of data and data are discarded if unrelated to the problem.<sup>67</sup> The researcher also evaluates the quality or credibility of the studies according to pre-determined criteria and determines if study limitations warrant exclusion of the data.<sup>68</sup> In the fifth stage, analyzing and interpreting the outcomes of the studies,<sup>67</sup> the reviewer summarizes and integrates the data using

methods appropriate to the level of the data and identifies patterns.<sup>67</sup> In the sixth stage, interpreting the evidence,<sup>67</sup> the researcher determines what conclusions can be drawn based on the patterns of data.<sup>67</sup> These conclusions may address whether the data supports or refutes the hypotheses in question and or the degree to which the results can be generalized to other situations.<sup>67</sup> In the seventh stage, presenting the results,<sup>67</sup> the reviewer disseminates the findings of the review.<sup>67</sup> How these procedures were implemented to address Specific Aim 1 is described in Chapter 2.

### **Qualitative Descriptive Method**

Qualitative Description (QD), as described by Sandelowski,<sup>65</sup> is a method used to comprehensively describe events related to a phenomenon of interest in everyday terms.<sup>65</sup> QD is often used in health sciences because it allows description of the experiences of persons who share common health challenges.<sup>65</sup> QD is considered naturalistic inquiry as it focuses on the description of phenomena as they occur naturally in participants' everyday lives. Researchers aim to create surface descriptions of participant experiences in straight-forward terms rather than producing highly complex, theoretical or conceptual renderings.<sup>65</sup>

Purposeful sampling, which is selection of individuals who are knowledgeable about a given experience, is often used in QD studies.<sup>69</sup> Researchers use semi-structured interviews to allow individuals to describe the "who, what, and where" of the phenomena in their own words<sup>65</sup> with the goal of obtaining as many varied, information-rich pieces of data possible.<sup>65</sup> Data collection can also include focus groups and observation of events or artifacts.<sup>65</sup>

When analyzing data using this method, researchers stay close to the participants' descriptions by using low-inference strategies such as coding and categorizing narrative text. Data are organized and presented in a way that best fits the data.<sup>65</sup> Data may be arranged in chronological order related to the trajectory of the

phenomenon or in the order of frequency with which participants discuss certain topics or concerns<sup>65</sup> The low-inference strategies increase the likelihood of researchers' consensus on how data are represented.<sup>65</sup> QD yields a comprehensive summary of the main characteristics of participants' experiences that can be used to answer pragmatic questions.<sup>65</sup> The implementation of QD methods to answer Specific Aims 2 and 3 are described in Chapters 3 and 4.

*Credibility.* Reliability and validity in the traditional sense often do not apply in QD studies. However, the credibility of QD studies is enhanced by procedures aimed at increasing the descriptive and interpretive validity and transferability of the findings.

Descriptive validity, as described by Sandelowski,<sup>65</sup> is the accurate and objective reporting of events.<sup>65</sup> In interview studies, descriptive validity depends on participants' narratives being collected, recorded, transcribed, and represented accurately. In this study, interview guides were developed to encourage participants to describe all aspects of their pain experiences with as much detail as they were able. The interviews were audiotaped and transcribed verbatim by a professional transcriptionist. The primary researcher then compared each transcript with the audio recording to ensure accuracy.

Interpretive validity, as described by Sandelowski,<sup>65</sup> reflects how well the researcher captures the meaning of events described by participants. Many analytic decisions made in this study were low inference, as is consistent with the QD methods, and thus offered little threat to interpretive validity. However, when interpretive decisions were made, such as how to group codes into categories and what to label the categories, several procedures were used to enhance the interpretive validity of the findings. First, an audit trail was maintained to provide a written record of all analytic decisions. This ensured that these decisions were made systematically and were well-grounded in the data. Second, all analytic decisions that involved a higher degree of interpretation were made by discussion and consensus among the primary investigator



and her dissertation advisors and were always informed by a re-examination of the original transcripts. Third, emerging categories were presented to subsequent participants who were asked about the relevance of these categories to their own experiences. Their responses were used to refine or modify the categories.

Transferability, according to Charmaz, is the process of showing that results of qualitative studies, while not generalizable in the traditional sense, can be applied in other contexts.<sup>70,71</sup> Transferability is enhanced when researchers provide a detailed description of the setting in which the data were collected and the participants who comprised the sample. This information allows consumers of the research to determine if the results apply to their setting and population of interest. For this study, an in-depth description of the hospital system and the unit on which the study took place are provided as is a considerable amount of demographic and medical information related to the participants who were interviewed. Threats to validity and transferability due to study limitations are discussed in Chapters 3 and 4.

### **Structure of the Dissertation**

The remainder of this dissertation is structured as follows. Chapter Two is an integrative review of the literature related to post-craniotomy brain tumor pain (Aim 1). Sections of this chapter were integrated in a study published in the *Journal of Advanced Nursing*.<sup>16</sup> Chapter Three presents the finding of a qualitative descriptive study that describes how persons who have undergone a craniotomy for the excision and removal of a brain tumor describe the quality of their pain during the post-surgical period (Aim 2). Chapter Four presents the finding of a qualitative descriptive study that describe how persons who have undergone a craniotomy for the excision and removal of a brain tumor describe their pain management experiences during the post-surgical period (Aim 3). Chapter Five summarizes and synthesizes the main findings of the integrative review and the qualitative descriptive studies, discusses clinical implications of the overall

findings of the dissertation projects, and makes recommendations related to future post-craniotomy pain research.

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## **CHAPTER TWO**

This chapter present the results of an integrative review which examined the evidence of pain and associated symptoms among adult (> age 21), post-craniotomy, brain tumor patients who had been hospitalized on intensive care units.



## Introduction

### Background

Brain tumor is the seventeenth-most diagnosed cancer worldwide, with 256,000 new cases of brain tumor diagnosed in 2012.<sup>72</sup> Men suffer from brain cancer slightly more frequently than women<sup>72-75</sup> and incidence rates are higher in developed countries than in lesser developed countries.<sup>72-74</sup> Scientific advances have resulted in improvements in the diagnosis and treatment of brain tumors.<sup>72</sup> In fact, one- and five-year survival rates have increased from 7.3% in 1970 to over 18% in 2011.<sup>75-78</sup>

Approximately 90% of patients with brain tumors undergo craniotomies for excision and removal of the tumor to increase survival.<sup>79</sup> Surgical procedures are generally understood to be painful<sup>80</sup> but less is understood about post-craniotomy pain. Healthcare providers commonly believe that craniotomies are less painful than other types of surgery due to lack of innervation in the brain<sup>81,82</sup> and are thus less apt to treat pain. In addition, post-craniotomy pain is often untreated or undertreated due to concerns that it may mask neurological changes in these patients.<sup>83-85</sup> Pain is often associated with other symptoms including anxiety and depression<sup>80,86</sup> and nausea and/or vomiting.<sup>87</sup> Understanding post-craniotomy pain in brain tumor patients is important because post-operative pain is a common cause of delayed mobilization,<sup>88</sup> lengthened hospital stay,<sup>88-90</sup> disability and decreased quality of life.<sup>91,92</sup> In addition, research has shown that under-treated, generalized post-operative pain is a predictor of the development of persistent pain.<sup>93-97</sup> To date, post-craniotomy pain and the symptoms associated with it is poorly understood. Researchers have called for additional studies to understand influencing factors and associated symptoms of post-craniotomy pain and to determine how to best treat it to prevent negative health outcomes.<sup>83,86,98-100</sup>

## Definitions and Theory

The International Society for the Study of Pain describes pain as a subjective sensory and emotional experience.<sup>80,94,101</sup> Pain is a complex symptom comprised of at least four dimensions (intensity, affect, quality, and location).<sup>102,103</sup> Physical, psychological, social, and cultural factors influence the experience of pain.<sup>88,104</sup>

The Theory of Unpleasant Symptoms (TOUS), which suggests that symptoms such as pain are multidimensional and interactive, is commonly used to support pain research because it is relevant to practice and can be used as a framework for making decisions related to patient care.<sup>105,106</sup> The TOUS includes three main concepts: (1) physiological, measureable *symptoms* experienced by the patient; (2) *influencing factors* which alter the patient's experience of the symptom; and (3) patient *performance*.<sup>106,107</sup> *Influencing factors* are physiological, psychological, and situational in nature and can catalyze each other affecting patient performance.<sup>106,107</sup> *Performance* is the impact of the symptom on patient outcomes including functional performance (the ability to physically function) and cognitive performance (the ability to think).<sup>106,107</sup> Researchers using the TOUS have termed groups of associated symptoms as "*clusters*."<sup>75,107</sup> This review will also use the term *cluster* to identify these groups of co-related symptoms.

## The Review

### Aim

The aim of this study was to conduct an integrative review using the TOUS as a guiding framework to synthesize and examine what is known about the phenomenon of pain in adult ( $\geq 21$  years of age), post-craniotomy, brain tumor patients. Specifically, this review sought to answer the following research questions: (1) What is the evidence for post-craniotomy, post-brain tumor pain in adult ( $\geq 21$  years of age) patients hospitalized on intensive care units?; and (2) What is the evidence for a post-craniotomy symptom

cluster associated with pain in adult ( $\geq 21$  years of age) patients hospitalized on intensive care units?

## **Design**

Cooper's<sup>108</sup> integrative review method guided the review. This method of integrative review was chosen because it provides a systematic framework to synthesize the current literature regarding post-craniotomy pain in the brain tumor patient.<sup>109,110</sup>

Cooper's method includes seven stages: advance formulation of the problem, data collection, data extraction, evaluation, analysis, interpretation, and presentation of the results.<sup>110</sup> The formulation of the problem, the first stage of the method, was informed by a preliminary literature search and the researchers' clinical experience that suggested a greater understanding of acute post-craniotomy pain was warranted. The authors felt an integrative review was necessary to synthesize the current literature and further the state of the science.<sup>109,110</sup>

## **Search Methods**

Data collection, the second stage, consisted of a literature search. Studies were identified for inclusion by purposive searching of electronic databases including Medline, OVID, PubMed, and CINAHL. In addition, hand-searching of references and an examination of citations from identified published reviews were conducted. Two experienced reference librarians provided consultation on the search process. Search terms for all databases and searches included traumatic brain injury; pain, postoperative; brain injuries; postoperative pain; craniotomy; decompressive craniectomy; and trephining. Inclusion criteria were as follows: (1) data-based quantitative and qualitative articles focused on post-craniotomy pain in adult brain tumor patients aged 21 or older; (2) published between 1/1/2000 and 12/31/2014; (3) English-language; (4) neurosurgical inpatients; and (5) intensive care unit settings. Abstracts, editorials, dissertations,

theses, reviews, and articles concerning intraoperative pain control, end-of-life care, or institutional practices were excluded.

### **Search Outcome**

The search strategy generated 115 studies. The studies which were recorded in a Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) diagram. (See Figure 2.1.) A total of 109 potentially relevant studies remained after the initial screening of titles for duplicates, publication in English, and publication dates. The remaining abstracts were reviewed for type of study, population, study setting, and discussion of pain. After application of the inclusion and exclusion criteria, we eliminated 83 additional articles from review, including five qualitative studies that either did not meet inclusion criteria because they did not focus on pain or the participants were not in-patients. This resulted in a sample of 26 quantitative articles to be reviewed in full-text format. (See Table 2.1). Data from eligible studies were abstracted into tables listing general information, level of evidence, and concepts defined in the TOUS.

### **Quality Appraisal**

In the third stage, two authors completed a quality appraisal on the 26 articles. Using a 3-point scale (yes, no, unclear) described by Gazarian, they rated the studies on nine criteria including aims, design, methods, sample, ethical considerations, results, limitations, implications, and sponsorship.<sup>111</sup> The studies were also appraised for bias using the Cochrane Risk of Bias tool. Twenty-one of the studies used a randomized design. Of the five studies that did not use randomization, two were retrospective,<sup>112,113</sup> and three were prospective trials.<sup>114-116</sup> The team determined that these five studies nonetheless met inclusion criteria and thus all 26 studies are included in the review.

### **Data Abstraction**

The fourth stage includes data analysis and interpretation.<sup>108</sup> In this stage, all of the included studies were read in full and relevant data were extracted and tabulated.

Table 2.1 displays the authors' names; dates and countries of publication; purpose and design; sample, setting and intervention; medication tested; and pain prevalence, incidence, and intensity. (See Table 2.1).

### **Data Synthesis**

In the fifth and final stage, the tabulated data were synthesized to address the research questions.<sup>108</sup> The authors grouped the data into categories suggested by the TOUS including incidence of pain, influencing factors, cluster, and patient performance. (See Table 2.2). Two of the authors (RG & DV) reviewed each study and verified the accuracy of data as presented and over several meetings compiled the results.

## **Results**

### **Description of the Studies**

Of the 26 studies included, all were pharmacological pain management trials (pain medications) and most were randomized, controlled trials (RCTs) (n = 21). The studies included 1892 total patients and were originally designed to test local wound infiltration or medications to control pain (intravenous, intramuscular, oral medications, nerve blocks, general anesthesia) (See Table 2.1). The medications that were tested varied but mostly included bupivacaine, ropivacaine, tramadol, parecoxib, paracetamol, and morphine.

The mean ages of the participants in the studies ranged from 45 to 55, and approximately equal numbers of men and women were represented. The comprehensive search identified five qualitative studies; however, these did not meet inclusion criteria (focus not on pain or participants not in-patients) and were excluded from final analysis. The majority of trials took place outside of the United States at non-profit, urban, academic medical institutions. Only one study reported racial characteristics of the sample that consisted mostly of Caucasians (52 versus 12 non-

Caucasian).<sup>117</sup> Reports included both supratentorial surgeries and infratentorial surgeries with mean lengths of surgery ranging between 200 and 300 minutes.

## **Main Results**

As previously discussed, we used the TOUS as the guiding framework for describing the experiences and cluster associated with post-craniotomy pain in brain tumor patients, which resulted in five categories: (1) evidence of pain; (2) manner of pain assessment; (3) influencing factors; (4) symptom cluster; and (5) patient performance (Tables 2.1 and 2.2).

*Evidence of Pain.* Fifteen studies reported specific percentages of participants experiencing moderate-severe pain. These percentages were as high as 60-96% within the first two days after surgery, despite the use of analgesics. Participants in eight studies required additional pain medications, and in one study, inadequate analgesia in 75% of participants necessitated the removal of one study arm.<sup>118</sup> Within this arm, six of eight patients experienced inadequate analgesia and multiple infusions of additional pain medication were required to reduce pain intensity scores to below 30 (out of 100).<sup>118</sup> An additional study reported the withdrawal of five participants for severe pain in the first post-operative hour.<sup>119</sup>

*Manner of Pain Assessment.* Measures that were used to assess pain varied but most used one-dimensional assessments of intensity including visual analogue scales (VAS), numerical rating scales (NRS), visual rating scales (VRS), or visual numeric scales (VNS). Study authors did not measure other dimensions of pain such as timing, distress, affect, and quality. Twenty-one studies (81%) identified inadequate pain relief.

*Influencing factors.* Table 2.2 displays the evidence of post-craniotomy pain, factors that may influence its development, an associated symptom cluster, and possible impact on patient performance. Many authors did not report all elements of the TOUS.

Eleven of the 26 studies (42%) discussed some physiological, psychological, or situational factors influencing post-craniotomy pain.

Several studies examined physiological influencing factors such as included gender and age but findings were inconsistent. One study found that women tended to experience higher pain levels than men<sup>117</sup> while another study found that men were more likely to ask for pain medication than women.<sup>120</sup> The impact of age in the development of post-craniotomy pain also was not clear. One study found that older age was associated with less pain<sup>112</sup> while another found increased pain levels in older patients.<sup>121</sup>

Psychological influencing factors are the patient's emotional reactions to the disease and can include mood and perceived level of self-sufficiency.<sup>106,107</sup> No studies examined psychological factors that may influence the experience of post-craniotomy pain.

Situational factors are found in the social and physical environment and can include surgical positioning, site of surgery, and use of anesthetics. Three studies reported less pain among patients with frontal craniotomies,<sup>112,113,116</sup> and one study found that perioperative nerve blockade decreased the incidence of post-operative pain.<sup>117</sup> General anesthetics used included sevoflurane and desflurane. The use of sevoflurane resulted in less pain in one study,<sup>122</sup> while in another, patients receiving sevoflurane required additional medication to control their pain.<sup>123</sup>

*Clusters.* Clusters in the TOUS are groups of co-related symptoms that interact, affecting the patient's symptom experience.<sup>106,107</sup> Although the researchers did not explicitly explore 'symptom clusters,' 21 (81%) studies discussed symptoms related to pain. Symptoms reported include headache nausea and vomiting, shivering, fatigue, dizziness, respiratory depression, constipation, neurologic changes, increased risk of intracranial bleeding, and agitation. The top three most common symptoms described

were nausea (15 studies; 58%), vomiting (16 studies; 62%), and changes in blood pressure including, but not limited to, the development of hypertension (9 studies, 35%).

*Patient performance.* Patient performance is frequently assessed in terms of tangible functional outcomes, such as length of stay, readiness to be discharged, and perceived quality of life. Although performance related to post-craniotomy pain was not explicitly examined, almost half of the studies described potential results of post-craniotomy pain (See Table 2.2). However, it was unclear if the impact on patient performance was a direct result of pain, the use of pain medication, or other factors. Other functional performance outcomes reported included increased cost of medication and increased hospital length-of-stay. In two different studies, poorly managed post-craniotomy pain resulted in delayed discharge and altered quality of life.<sup>113,120</sup> Four studies described changes in cognitive performance using the proxy measure of level of conscious assessed by the Glasgow Coma Scale (GCS).<sup>122-125</sup> Two studies found changes in level of consciousness due to type and amount of analgesic used<sup>124,125</sup> and one identified these changes as being the result of uncontrolled pain.<sup>122</sup>

## **Discussion**

To our knowledge, this is the first integrative review of data-based studies examining: (1) evidence for post-craniotomy, post-brain tumor pain; and (2) the evidence for a post-craniotomy pain symptom cluster in brain tumor patients. Brain tumors affect many worldwide and pain has been identified as a public health priority. Accordingly, most research on post-craniotomy pain has been conducted in other countries. Research to date has focused solely on pharmacological intervention and fails to explore the multidimensional nature of pain through comprehensive assessment.<sup>126-129</sup> Although pharmacological interventions exist, no one therapeutic medication has been identified as most efficacious.<sup>88,130-132</sup> Our review found that despite the use of 18 different analgesics, moderate to severe pain still occurred among post-craniotomy brain tumor



patients and that many patients expressed inadequate pain management resulting in the need for more analgesics. This review provides strong evidence for the existence of post-craniotomy pain and the need for more research to develop evidence-based practice guidelines in this population.

While researchers have begun to study patients' subjective experiences after craniotomy, such as their fears, expectations, and satisfaction,<sup>133,134</sup> these investigations have not yet addressed pain. Patients' experiences of pain will necessarily be affected by amount of pain control and healthcare provider interaction, but the extent to which these influence post-craniotomy, post-brain tumor patient experience has not yet been made clear. Due to the complicated nature of post-craniotomy pain, further research is warranted to provide evidence-based care.

A full understanding of the post-craniotomy pain experience from the patients' perspectives would improve assessment of pain, planning of interventions, and evaluation of care.<sup>91,94,104</sup> This review serves as a call to action to describe the context and unfolding of post-craniotomy brain tumor pain from the patient's perspective and provides evidence to challenge the commonly held belief that post-craniotomy pain is not an important problem.<sup>81,82</sup>

The intensity of post-craniotomy, post-brain tumor pain is well-documented. Measures such as VASs are capable of reflecting this intensity and change in pain over time.<sup>103</sup> However, pain intensity is not necessarily correlated with level of patient distress and resulting patient performance.<sup>94,103,104,135,136</sup> Consequences such as the development of dysfunction and disability reflect broader dimensions of pain that cannot be assessed by mere measures of intensity and distress.<sup>94,136</sup> Current research fails to explore the pain experience beyond intensity and does not address the cluster of associated symptoms that may magnify pain and/or moderate treatment effects.

The limited and conflicting nature of the evidence concerning physiological factors that influence the development of post-craniotomy pain in the brain tumor patient suggests that additional, more comprehensive description is needed. Increased awareness of the experiences of post-craniotomy pain across age groups is needed.<sup>91</sup>

Investigations of the experience of post-craniotomy, post-brain tumor pain by gender could lead to the development of targeted approaches for men and women. Similarly, while incidence of brain tumor is higher in Caucasians than in those of other racial backgrounds,<sup>79</sup> few authors report racial characteristics of the study sample, preventing clear understanding of the manner in which post-craniotomy pain unfolds among different groups.

Psychological factors influencing the development of post-craniotomy, post-brain tumor pain are also thought to be important.<sup>80,91,104,106,135</sup> None of the studies in the review, however, addressed these factor and thus it is not yet clear what role emotions, mood, and perceived level of self-sufficiency play in the unfolding and experience of post-craniotomy pain.

Situational factors that affect the unfolding and experience of post-craniotomy pain also need further clarification. Longer surgical time influences length of intensive care unit stays in cardiac patients<sup>137</sup> and length of surgery influences the severity of post-operative pain in ambulatory care surgical patients.<sup>89</sup> In post-craniotomy patients, longer surgeries may increase post-surgical pain due to greater time spent in surgical positions, increased duration of muscle retraction, larger incisions, and the potential for more involved surgical procedures.<sup>90,113</sup> Researchers should therefore investigate the impact of length of surgery on the development of post-craniotomy pain.

More detailed comparisons could also be made if surgical diagnoses were consistently reported. For example, it is known that post-operative headache in occipital surgeries stems from resulting occipital neuralgia.<sup>113</sup> Examining the effect of surgical

location on development of post-craniotomy headache could lead to better targeted interventions.

The existence of a symptom cluster would call for comprehensive post-craniotomy pain assessment.<sup>88,91,104</sup> Little is known, however, about the cluster associated with post-craniotomy, post-brain tumor pain. Within the current science, effects of pharmaceutical interventions, post-craniotomy pain, other symptoms such as pain and anxiety, and patient performance are often confounded. Research that explicates the nature of symptom clusters in this population is needed.

Literature shows that post-operative pain may affect performance by increasing length-of-stay, cost of hospitalization, and delaying discharge.<sup>88,94</sup> Some research links post-craniotomy pain to increased length of stay and delayed readiness to be discharged in the traumatic head injury population.<sup>138,139</sup> However, only a few studies have examined the impact of post-craniotomy pain on brain tumor patients' functional and cognitive performance.

Within the broader pain literature, untreated acute pain has been correlated with the development of long-term pain due to nervous system plasticity.<sup>94,104,113,135</sup> In addition, researchers of general post-surgical pain have shown that inadequate post-operative analgesia has led to the development of persistent pain.<sup>80,94,140</sup> Batoz *et al.*<sup>141</sup> have shown that improved pain management in post-craniotomy patients during the acute post-operative period decreases the development of persistent pain at two months, but the relationship between post-operative pain management and persistent pain has not been well-studied in post-craniotomy brain tumor patients. Therefore, describing the connection between post-craniotomy pain and patient performance could lead to the development of interventions to prevent or minimize both post-craniotomy pain and its resulting effects.

Over forty years of research have repeatedly illustrated that pain is under-assessed, under-recognized, and undertreated. The treatment of post-craniotomy pain is further complicated by a lack of understanding of the manner in which it unfolds over the course of the post-operative period and a reluctance to treat it aggressively for fear of masking neurological changes. The result is an unclear risk-benefit ratio associated with the treatment of post-craniotomy pain in brain tumor patients. Additional research would illuminate the relationship between post-craniotomy pain, influencing factors, associated clusters, and patient performance, leading to the development of timely interventions to control pain without increasing risk to patients.

### **Limitations**

This review was limited to examining studies that discussed particular influencing factors, associated clusters, and the effect of post-craniotomy, post-brain tumor pain on patient performance. It is possible that studies looking at post-craniotomy pain within a different context were missed. In addition, this review does not represent ongoing or unpublished studies, nor does it include published work that has not undergone the peer review process.

### **Conclusion**

Evidence suggests that post-craniotomy, post-brain tumor patients experience significant post-surgical pain but no guidelines have been established to treat this pain. Post-craniotomy pain may influence length of hospital stay, cost of medications, quality of life and development of persistent pain. However, little research has been conducted on the complex nature and experience of post-craniotomy, post-brain tumor pain. Mitigating or preventing post-craniotomy pain in the brain tumor population will likely result in improved patient outcomes. Patient-centered outcomes research should focus on attempting to understand post-craniotomy pain, which will pave the way for the

development of timely interventions and standardization of treatment for post-craniotomy pain to improve functional outcomes and quality of life.

Figure 2.1. PRISMA Diagram of Systematic Search

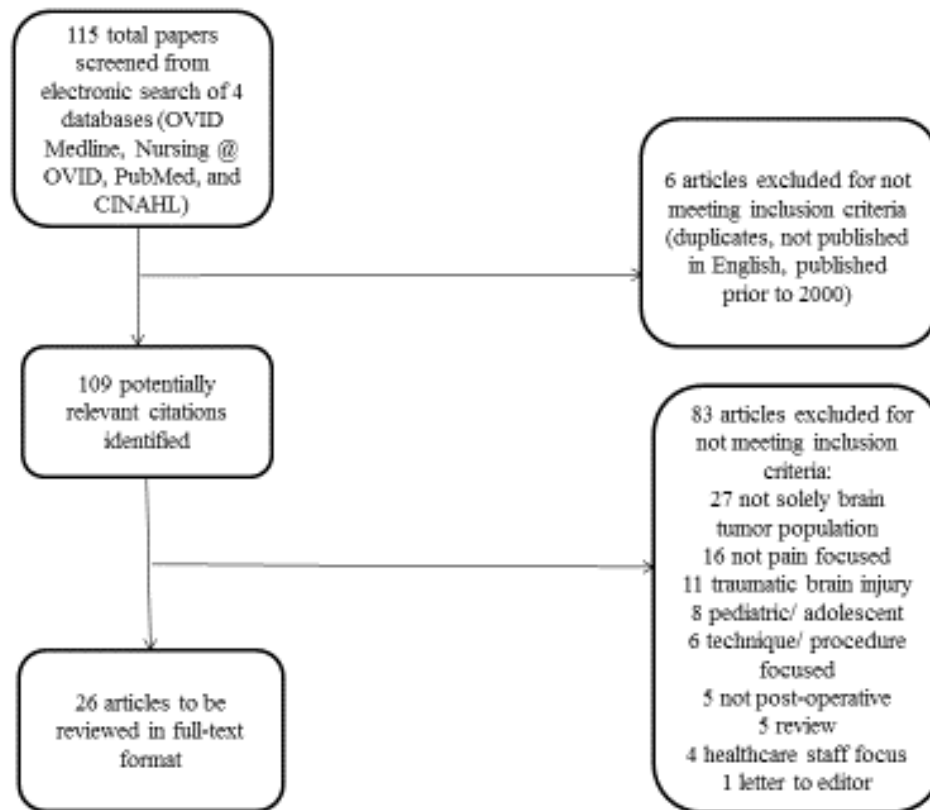


Table 2.1. Summary of Studies

Author, Year, Country	Design, Sample Size, Medication	Existence of Pain and Pain Intensity, Rating Scale Used
Bala et al. (2006) India	Prospective, double-blind RCT; <i>N</i> = 40 <u>Medication</u> : Scalp nerve block (bupivacaine)	60% experienced moderate-severe pain in first 12h post-op (control) 25% experienced moderate-severe pain in first 12h post-op (intervention) <u>Rating Scale</u> : NRS; scores 0-22.5 out of 100
Batoz et al. (2009) France	Prospective, single-blinded study; <i>N</i> = 52 <u>Medication</u> : Incisional infiltration (ropivacaine); nalbuphine post-surgery	VAS scores higher in control group Persistent pain significantly lower in intervention group at 2 months (56% in control group vs. 8% in intervention group) <u>Rating Scale</u> : VAS; scores 0-35 out of 50
Biswas and Bithal (2003) India	Prospective, double-blind RCT; <i>N</i> = 50 <u>Medication</u> : Incisional infiltration (bupivacaine) vs. fentanyl	Additional medication needed in 60% of bupivacaine group and 57% of fentanyl group <u>Rating Scale</u> : VAS; scores 0-4 out of 10
Ducic et al. (2012) United States	Retrospective interview of patients; <i>N</i> = 7 <u>Medication</u> : None tested	86% experienced pain greater than 80% on migraine index <u>Rating Scale</u> : VAS; scores 2-10 out of 10
Ferber et al. (2000) Poland	Multi-stage prospective study; <i>N</i> = 35 <u>Medication</u> : Intravenous tramadol	Pain relief in 50% of patients receiving one dose; in 88% of patients receiving 2 or 3 doses <u>Rating Scale</u> : VRS; scores 0-4 out of 5
Girard et al. (2010) Canada	Prospective, double-blind RCT; <i>N</i> = 30	Similar pain scores between nerve block and morphine groups <u>Rating Scale</u> : NRS; scores 2-7 out of 10

	<u>Medication:</u> Cervical plexus nerve block (lidocaine and bupivacaine) vs. intravenous morphine bolus	
Grossman et al. (2007) Israel	Open, prospective, double-blind non-randomized, placebo- controlled study; <i>N</i> = 40  <u>Medication:</u> Incisional infiltration (lidocaine and bupivacaine); metamizol intra-operatively	13 patients needed additional pain medication <u>Rating Scale:</u> NRS; scores 0-4 out of 10
Irefin et al. (2003) United States	Prospective study; <i>N</i> = 128 <u>Medication:</u> None tested	No significant difference in pain scores between groups <u>Rating Scale:</u> VAS; scores 0-5 out of 10
Jellish et al. (2006) United States	Prospective, double-blind RCT; <i>N</i> = 120 <u>Medication:</u> PCA (morphine or morphine plus ondansetron)	Up to 76% experienced post-op pain Administered analgesia was inadequate <u>Rating Scale:</u> VAS; scores 4.5-6.1 out of 10
Jones et al. (2009) Australia	Prospective, double-blind RCT; <i>N</i> = 50 Medication: Intravenous parecoxib; morphine post-operatively	89% of patients required additional pain medication (morphine) Pain scores significantly lower in parecoxib group only at 6 hours <u>Rating Scale:</u> VAS; scores 0-35 out of 100
Law-Koune et al. (2005) France	Prospective, double-blind RCT; <i>N</i> = 80 <u>Medication:</u> Incisional infiltration (bupivacaine plus epinephrine) vs. ropivacaine	Placebo group received more morphine than bupivacaine or ropivacaine groups (22.2 mg; 12.7 mg; 10.5 mg, respectively) <u>Rating Scale:</u> VAS; scores 0-7 out of 10
Magni et al. (2005) Italy	Prospective, randomized, open-label clinical trial; <i>N</i> = 120 <u>Medication:</u> General anesthesia (sevoflurane-fentanyl vs. propofol-remifentanyl)	10% of ropivacaine group and 6% of sevoflurane group experienced pain at 45 minutes <u>Rating Scale:</u> VAS; scores unclear out of 100



Magni et al. (2009) Italy	Prospective, double-blind RCT; <i>N</i> = 120 <u>Medication</u> : General anesthesia (sevoflurane vs. desflurane)	22% of sevoflurane group and 17% of desflurane group required additional medication for pain <u>Rating Scale</u> : VAS; scores unclear out of 100
Morad et al. (2009) United States	Prospective RCT (unblinded); <i>N</i> = 64 <u>Medication</u> : as needed intravenous fentanyl vs. PCA (fentanyl)	Patients in PCA group had significantly lower pain scores than PRN group (2.53 versus 3.62, respectively) PCA group received significantly more fentanyl <u>Rating Scale</u> : NRS; scores 2-4.7 out of 10
Nair and Rajshekhar (2011) India	Prospective longitudinal study; <i>N</i> = 43 <u>Medication</u> : Oral paracetamol	5% had moderate pain in first post-op hour Significant pain reported by 63% of patients during first 48h; severe pain in 12% within first 12h; incidence decreased over first 48h <u>Rating Scale</u> : VAS; not stated out of 10
Nguyen et al. (2001) Canada	RCT; <i>N</i> = 30 <u>Medication</u> : Scalp nerve block (ropivacaine)	70% of patients in saline group experienced moderate pain in first 48h post-op <u>Rating Scale</u> : VAS; scores 1.6-4.4 out of 10
Rahimi et al. (2006) United States	Prospective, single-blinded RCT; <i>N</i> = 27 <u>Medication</u> : Oral narcotics vs. oral COX-2 inhibitors	Pain scores significantly higher in narcotics-alone group than COX-2 group ( $p = 0.003$ ) <u>Rating Scale</u> : VAS; scores 2-5.3 out of 10
Rahimi et al. (2010) United States	Prospective, blinded RCT; <i>N</i> = 50 <u>Medication</u> : Oral narcotics vs. tramadol	Tramadol group had significantly lower pain scores than narcotics-alone group ( $p < 0.005$ ) Pain scores between groups significantly different ( $p = 0.001435$ ) <u>Rating Scale</u> : VAS; scores 1-8 (narcotics-alone group), 0-7 (tramadol group) out of 10
Saringcarinkul and Boonsri (2008)	Prospective, double-blind RCT; <i>N</i> = 50	33% of bupivacaine group pain free at 30 minutes; decreased to 4% at 8 hours

Thailand	<u>Medication</u> : Incisional infiltration (bupivacaine)	16% of control group pain free at 30 minutes; decreased to 4% at 1 hour <u>Rating Scale</u> : VNS; scores 2.5-3.5 out of 10
Simon et al. (2011) Hungary	Prospective RCT; <i>N</i> = 90 <u>Medication</u> : Pre-operative oral diclofenac	Significant difference in incidence of pre-operative headache between intervention and control groups ( $p = 0.0045$ ) 77.7% experienced pain (first post-op day); 69.4% experienced pain (fifth post-op day) <u>Rating Scale</u> : VAS; scores 0-9 out of 10
Sudheer et al. (2007) Wales	Prospective RCT; <i>N</i> = 60 <u>Medication</u> : PCA (morphine vs. tramadol) vs. intramuscular codeine	4 patients did not require additional medication in first post-operative hour; 5 had severe pain necessitating withdrawal from study Less pain in morphine and codeine groups; significant residual pain noted in tramadol group <u>Rating Scale</u> : VRS; scores 0-10 out of 10
Thibault et al. (2007) Canada	Retrospective chart review; <i>N</i> = 299 <u>Medication</u> : None tested	24% experienced mild pain, 51.5% moderate pain, and 24.5% severe pain Overall prevalence of pain = 76% <u>Rating Scale</u> : VRS; scores unclear out of 10
Ture et al. (2009) Turkey	Prospective RCT; <i>N</i> = 80; 75 completed study <u>Medication</u> : Oral gabapentin vs. oral phenytoin	Pain scores significantly higher in phenytoin group at 15, 30, and 60 minutes ( $p < 0.001$ ) Total morphine consumption significantly higher in phenytoin group ( $p = 0.01$ ) <u>Rating Scale</u> : VAS; scores 0-4 out of 10
Verchere et al. (2002) France	Prospective, blind, RCT; <i>N</i> = 64	Paracetamol-only group stopped quickly due to inadequate analgesia in 75% of patients

	<u>Medication</u> : Paracetamol vs. paracetamol plus tramadol vs. paracetamol plus nalbuphine	<u>Rating Scale</u> : VAS; scores 5-30 out of 100
Williams, Pemberton and Leslie (2011) Australia	Prospective, double-blind RCT; <i>N</i> = 100 <u>Medication</u> : Intravenous parecoxib	70% of control group and 61% of parecoxib group needed additional pain medication <u>Rating Scale</u> : VAS; scores 2-5 out of 10
van der Zwan et al. (2005) The Netherlands	Prospective, double-blind RCT; <i>N</i> = 50 <u>Medication</u> : Remifentanyl vs. fentanyl	No significant difference in pain intensity between groups 13 of remifentanyl group (45%) required additional pain medication <u>Rating Scale</u> : VAS; scores 1-4 out of 10

RCT: randomized controlled trial; 4NRS: numerical rating scale; VAS: visual analogue scale; VRS: visual rating scale; VNS: visual numeric scale.

Table 2.2. Summary of Studies Using Theory of Unpleasant Symptoms Concepts

Author, Year	Influencing Factors	Symptom Cluster	Patient Performance
Bala et al. (2006)	<ul style="list-style-type: none"> <li>Length of surgery</li> </ul>	---	---
Batoz et al. (2009)	---	<ul style="list-style-type: none"> <li>Vomiting</li> <li>Agitation</li> <li>Shivering</li> <li>Hypertension</li> </ul>	---
Biswas and Bithal (2003)	---	<ul style="list-style-type: none"> <li>Change in diastolic blood pressure</li> </ul>	---
Ducic et al. (2012)	<ul style="list-style-type: none"> <li>Surgical site</li> </ul>	<ul style="list-style-type: none"> <li>Altered intracranial pressure</li> </ul>	<ul style="list-style-type: none"> <li>Altered quality of life</li> <li>Development of persistent pain</li> </ul>
Ferber et al. (2000)	---	---	<ul style="list-style-type: none"> <li>Change in systolic and/or diastolic blood pressure</li> <li>Changes in heart rate</li> <li>Changes in partial pressure of oxygen</li> <li>Altered intracranial pressure</li> </ul>
Girard et al. (2010)	---	<ul style="list-style-type: none"> <li>Nausea</li> <li>Vomiting</li> <li>Change in systolic blood pressure</li> </ul>	---
Grossman et al. (2007)	---	<ul style="list-style-type: none"> <li>Nausea</li> <li>Vomiting</li> <li>Elevated blood pressure</li> </ul>	---
Irefin et al. (2003)	<ul style="list-style-type: none"> <li>Gender</li> <li>Surgical site</li> </ul>	<ul style="list-style-type: none"> <li>Nausea</li> <li>Vomiting</li> </ul>	---

Jellish et al. (2006)	<ul style="list-style-type: none"> <li>• Surgical approach</li> <li>• Gender</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Headache</li> </ul>	<ul style="list-style-type: none"> <li>• Length of hospital stay</li> <li>• Patient satisfaction</li> <li>• Increased cost of medication used</li> <li>• Delayed discharge from hospital</li> </ul>
Jones et al. (2009)	---	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> </ul>	<ul style="list-style-type: none"> <li>• Sedation</li> </ul>
Law-Koune et al. (2005)	---	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Itching</li> <li>• Change in blood pressure</li> <li>• Bladder dysfunction</li> </ul>	<ul style="list-style-type: none"> <li>• Sedation</li> </ul>
Magni et al. (2005)	---	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Shivering</li> <li>• Change in blood pressure</li> <li>• Change in heart rate</li> </ul>	<ul style="list-style-type: none"> <li>• Change in Glasgow Coma Scale</li> </ul>
Magni et al. (2009)	---	<ul style="list-style-type: none"> <li>• Change in heart rate</li> <li>• Change in partial pressure of oxygen</li> </ul>	<ul style="list-style-type: none"> <li>• Need for reintubation</li> <li>• Changes in Glasgow Coma Scale</li> </ul>
Morad et al. (2009)	<ul style="list-style-type: none"> <li>• Gender</li> <li>• Age</li> <li>• Surgical site</li> <li>• Surgical approach</li> <li>• Perioperative neural blockade</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Change in blood pressure</li> <li>• Change in heart rate</li> <li>• Change in mean arterial pressure</li> </ul>	<ul style="list-style-type: none"> <li>• Neurological deterioration</li> </ul>

Nair and Rajshekhar (2011)	---	<ul style="list-style-type: none"> <li>• Agitation</li> <li>• Sympathetic Nervous System (SNS) stimulation</li> <li>• Altered blood pressure</li> <li>• Brain swelling</li> </ul>	<ul style="list-style-type: none"> <li>• Development of post-operative complications</li> <li>• Increased length of hospital stay</li> <li>• Increased mortality rate</li> </ul>
Nguyen et al. (2001)	<ul style="list-style-type: none"> <li>• Incisional site</li> </ul>	---	---
Rahimi et al. (2006)	<ul style="list-style-type: none"> <li>• Surgical site</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Respiratory depression</li> <li>• Constipation</li> <li>• Neurological changes</li> <li>• Constipation</li> </ul>	<ul style="list-style-type: none"> <li>• Altered mental status</li> <li>• Increased cost of medication used</li> </ul>
Rahimi et al. (2010)	---	---	<ul style="list-style-type: none"> <li>• Increased cost of medication used</li> <li>• Increased length of hospital stay</li> </ul>
Saringcarinkul and Boonsri (2008)	---	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> </ul>	<ul style="list-style-type: none"> <li>• Sedation</li> <li>• Change in Glasgow Coma Scale</li> </ul>
Simon et al. (2011)	<ul style="list-style-type: none"> <li>• Headache (presence prior to surgery increased post-surgical pain)</li> </ul>	---	<ul style="list-style-type: none"> <li>• Increased length of hospital stay</li> </ul>
Sudheer et al. (2007)	<ul style="list-style-type: none"> <li>• Surgical site (frontal associated with less pain)</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Change in partial pressure of oxygen</li> </ul>	---
Thibault et al. (2007)	<ul style="list-style-type: none"> <li>• Surgical site (frontal associated with less pain)</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> </ul>	---

	<ul style="list-style-type: none"> <li>• Age (increased age associated with lower pain scores)</li> <li>• Muscle reflection</li> </ul>		
Ture et al. (2009)	---	<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Dizziness</li> </ul>	---
Verchere et al. (2002)	---	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Shivering</li> <li>• Risk of intracranial bleeding</li> <li>• Agitation</li> <li>• Hypertension</li> </ul>	---
Williams, Pemberton, and Leslie (2011)	---	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> </ul>	<ul style="list-style-type: none"> <li>• Sedation</li> <li>• Change in Glasgow Coma Scale</li> </ul>
van der Zwan et al. (2005)	<ul style="list-style-type: none"> <li>• Age (increasing age experienced more pain)</li> <li>• Surgical site</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Vomiting</li> <li>• Change in partial pressure of oxygen</li> </ul>	---
<b>Total Studies Discussing Concept</b>	<b>11</b>	<b>21</b>	<b>14</b>

NRS: numerical rating scale; VAS: visual analogue scale; VRS: visual rating scale; VNS: visual numeric scale.

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### **CHAPTER THREE**

This chapter presents the results of a qualitative descriptive study of how persons diagnosed with a brain tumor who have had a craniotomy describe the quality of their pain during the post-surgical period.

## Introduction

Brain tumors account for between 85% and 90% of central nervous system tumors diagnosed in the United States.<sup>142,143</sup> Approximately 23,800 new cases of brain tumor were diagnosed in 2017.<sup>142,143</sup> Recent scientific advances that have resulted in improvements in the diagnosis and treatment of brain tumors have increased one- and five-year survival rates.<sup>143-147</sup> Approximately 90% of patients with brain tumors undergo craniotomies for treatment.<sup>148,149</sup>

Post-craniotomy pain is caused by a combination of skin incision and retraction and reflection of scalp muscles during surgery.<sup>150</sup> The scalp contains both large and small diameter nerve fibers that transmit pain signals to the brain when stimulated.<sup>151</sup> Post-craniotomy pain involves mainly superficial nerves in the scalp, muscles, and soft tissue throughout the head although surgical manipulation of the dura mater during surgery may also result in pain.<sup>147</sup> The nature of the pain experienced by post-craniotomy patients may be related to the surgical site as incisions in the subtemporal or suboccipital region are likely to produce more pain.<sup>147</sup> Head positioning during surgery may also play a role in the development of post-craniotomy pain.<sup>152</sup>

Despite the common belief that craniotomies are less painful than other types of surgery, researchers have found that pain in post-craniotomy patients is often underestimated and up to 93% of post-craniotomy patients experience moderate to severe nociceptive pain.<sup>148,149,153</sup> One recent review revealed that between 60% and 96% of post-craniotomy patients experience pain within the first two days after surgery despite the use of analgesics, with multiple doses of medications frequently needed to reduce patients' pain levels.<sup>154</sup> Alternatively, one study found patients experienced minimal pain after brain surgery, but these patients were given intravenous opioid analgesics and were observed for only 24 hours after the surgery.<sup>155</sup> While many studies

report that patients experience pain after surgery, the experience of such pain is poorly understood.

Because pain is salient during the post-surgical period of persons who have undergone a craniotomy, it is important that healthcare providers have a good understanding of the pain experience. One theory that provides a broad-based perspective on symptom experiences, including pain, is the Theory of Unpleasant Symptoms (TOUS).<sup>156</sup> According to the TOUS, symptoms can occur alone or simultaneously and can be caused by a single event (e.g., surgery) or develop over time.<sup>156</sup> The TOUS identifies three components of the symptom experience: the symptom(s), the influencing factors that cause or affect the nature of the symptom(s), and the results or consequences of the symptom(s).<sup>156</sup> Influencing factors include the physiologic, psychological, and situational factors that affect the experience of a symptom.<sup>156</sup> Consequences include the effects of symptoms on functional and cognitive performance.<sup>156</sup> The relationships among these three components are considered reciprocal rather than linear.<sup>156</sup> The theory also outlines four symptom dimensions: intensity (i.e., severity), timing (i.e., duration and frequency), distress (i.e., amount of bother perceived), and quality (i.e., how the symptom feels).<sup>156</sup> Each of these dimensions is distinct but interacts with the other dimensions to affect the overall symptom experience.<sup>156</sup>

Some of the TOUS dimensions of pain have been studied in post-craniotomy patients. These studies, however, have primarily measured only the intensity and timing dimensions of pain. For example, an integrative review of 26 studies of post-craniotomy pain in brain tumor patients revealed that most studies were randomized controlled trials of pharmacological pain management.<sup>154</sup> These studies measured primarily pain intensity and timing with visual analogue scales (VAS), numerical rating scales (NRS),

visual rating scales (VRS), or visual numeric scales (VNS)<sup>157-159</sup> and did not address other dimensions of pain such as pain quality.

In order to provide optimal pain care for patients with post-craniotomy pain, it is important to understand how patients experience not just the intensity and timing of the pain, but the quality as well. Because no studies have focused on this aspect of the pain experience in this population, the purpose of this study was to describe how persons diagnosed with a brain tumor who have had a craniotomy describe the quality of their pain during the post-surgical period.

## **Methods**

Qualitative Description (QD) methods as outlined by Sandelowski guided the study.<sup>160</sup> QD is a research approach frequently used in the health sciences to describe the experiences of persons who share a common health challenge in straight-forward terms. In order to generate information about the participants' experiences, semi-structured interviews are commonly used. Researchers use low inference analytic strategies to generate a surface description of participant experiences rather than more complex strategies that would be used to generate highly theoretical or conceptual renderings of the data. The product of QD is therefore a comprehensive summary of the main characteristics of the participants' experiences that can be used to answer pragmatic practice questions. Because our aim was to provide straightforward description of how patients described the quality of their post-craniotomy pain, QD methods were the most suitable for this study.

## **Setting**

Data were collected on the neurosurgical step-down unit of a large urban teaching hospital in the Midwest from February 2016 through December 2016. The hospital completes an average of 900 craniotomies for the treatment of brain tumors annually. The hospital's neurosurgical practice provides service for patients throughout

the Midwestern United States. The step-down unit has 23 beds with an average daily census of 23. Patients on this unit have undergone procedures for neurological illness and injuries, including craniotomies. They are clinically stable but have acute care needs that prevent transfer to medical-surgical acute care units. Standard post-surgical order sets that include a variety of recommended analgesics are utilized by the hospital's neurosurgical practice.

### **Inclusion and Exclusion Criteria**

Patients who had a craniotomy for the excision and removal of a brain tumor within the prior two weeks were recruited for the study. Other eligibility criteria including being age 21 years and older and speaking English fluently. Patients who were clinical unstable, actively psychotic, and or who had hearing, speech, or cognitive deficits that would interfere with full study participation were excluded.

### **Recruitment**

Prior to recruitment, institutional review board approval was obtained from the investigators' university and a waiver of authorization was obtained for the use of protected health information for study recruitment. The medical records of consecutive patients hospitalized for the treatment of primary brain tumors were reviewed weekly by the unit's Clinical Nurse Specialist (CNS) to determine study eligibility. The CNS generated a list of eligible patients, approached them, and obtained their verbal consent to be contacted by the study's primary investigator. The primary investigator then approached and greeted potential participants. Using a standard script, the primary investigator obtained verbal consent to describe the study, confirm eligibility, and discuss study requirements. For those patients who agreed to participate, written informed consent for the interview and for review of medical records was obtained. Participants were informed that study participation was voluntary and that they could withdraw at any time.



## **Data Collection**

In order to describe the sample, the following data were collected from the participants' medical records: (1) length of hospital stay; (2) participant age, gender, body mass index, and race/ ethnic background; (3) tumor type, grade, and location; (4) surgical approach, length of time, and head positioning; (5) documented pain ratings; (6) Glasgow Coma Scale ratings; (7) analgesics prescribed, dosages, and number of doses administered; (8) steroids prescribed, dosages, and number of doses administered; (9) prior pain history; and (10) prior opioid use.

Interviews were conducted in the participants' private hospital rooms by the primary investigator. The interview questions addressed the following topics: (a) how participants described their pain since surgery, (b) how they dealt with their pain, and (c) how healthcare providers managed their pain. For this study, prompts were used when needed to generate robust descriptions of participants' pain quality. If the participants did not describe the quality of their pain in detail, the primary investigator asked them to do so with prompts such as, "Tell me more about what the pain felt like to you. How would you describe it?" Interviews were audio-recorded and transcribed by a professional transcriptionist. When participants requested, families were present for interviews and in a few instances contributed to the interview. Because family members had not provided consent for participation, their words were redacted from the transcripts.

## **Data Analysis**

Descriptive statistics were used to describe the sample. Patient pain intensity ratings were summarized and averaged for each inpatient day. Patient Glasgow Coma Scale ratings were summarized and averaged for each inpatient day.

The analysis team was made up of the primary investigator, a doctoral student in nursing; a senior nurse researcher with expertise in qualitative methods, and a senior

nurse researcher with expertise in oncology. Using standard content analytic procedures, the team analyzed the data in several stages.<sup>161</sup>

Team members read through the transcripts multiple times in order to fully understand how the participants described the quality of their pain. The primary investigator highlighted and extracted text units (e.g., phrases, sentences, or stories) that captured how the participants described their pain, particularly its quality. The text units were coded with a word or phrase that captured their essence. The codes were verified by the other two team members. The codes were then categorized into different types of pain descriptors through team discussion and consensus.

The primary investigator placed the codes into a case-by-topic table for data display.<sup>162</sup> Cases were presented on the vertical axis and the categories were presented on horizontal axis. Codes were placed in appropriate cells. The codes in each column were summarized, and a narrative description of the categories in each column was written by the primary investigator. The narratives were confirmed by the other team members through a review of the transcripts.

While the categories represented unique types of pain quality, many participants described several different types of pain that often changed over the post-surgical period. The team therefore selected three specific cases that exemplified the complexity and progression of post-craniotomy pain. A brief case summary was written for each of these participants with a focus on how they described the quality of their pain over the post-surgical period.

## **Results**

### **Demographic and Medical Data**

Twenty-eight patients met study criteria and agreed to participate. One patient who initially agreed to participate was not interviewed because she was noted to be confused after providing consent, and none of her data were used in the study. Of the

remaining 27 participants, the medical record for one participant who was interviewed could not be accessed. Therefore, demographic and medical data are presented for 26 patients, while the qualitative findings are based on interviews with 27 patients.

Patients were interviewed between 2 and 11 days after surgery. Demographic and medical data were collected for 26 of the patients interviewed and are presented in *Table 3.1*. Participants were between the ages of 21 and 83 years. Sixteen participants were women, and 11 were men. Twenty-six of the participants were Caucasian, and one was African-American. The participants' lengths of hospital stay were between 3 and 13 days. Most participants had no history of opioid use and most had no prior pain history.

As seen in *Table 3.1*, the participant tumor types were diverse with glioma/ glioblastoma/ oligodendroglioma/ oligodendroma and meningioma being the most common. All grades of tumors were represented with grade 1 tumors being the most common. The location of tumors included the frontal, frontotemporal, temporal, and posterior fossa regions. The participants' tumors were located fairly equally in the right and left hemispheres. The length of surgeries ranged between 150 and 984 minutes, an anterior approach was used in more than half of the surgeries, and the majority of participants received sedation. The most frequently prescribed post-surgical analgesics were fentanyl, hydrocodone-acetaminophen, acetaminophen, oxycodone-acetaminophen, and hydromorphone. Most of the participants were also prescribed dexamethasone.

## **Interviews**

The interviews lasted between 7 and 50 minutes and averaged 30 minutes. The majority of participants were oriented and alert, although a few were oriented but lethargic. Some participants provided elaborate, in-depth descriptions of their pain quality, while others needed more interviewer probing to describe their pain. Many participants reported their pain had subsided, while a few were in pain during the

interview. The participants' demeanor varied during the interviews. Most were in good spirits and eager to participate whereas some appeared irritable and frustrated and questioned why their pain was important to discuss. A few were tearful.

### **Quality of Pain**

The participants described the quality of their pain with six different types of descriptors. We labeled the six types of pain quality descriptors as follows: *pain as pressure*, *pain as tender or sore*, *pain as stabbing*, *pain as throbbing*, *pain as jarring*, and *pain as itching*. Because we used common word use definitions to categorize and label the participants' pain quality descriptors into the six types, these definitions are included below. In some cases, the participants used the word we chose as a label, whereas in other cases they described their pain with different words that conveyed the same or similar pain quality. While the focus of this analysis was on the quality of the participants' pain, for each pain quality type we discuss relevant participant comments about the intensity, timing, or location of that type of pain. A few participants did not describe the quality of their pain, but instead focused only on the intensity, timing, or location of their pain.

### **Pain as Pressure**

Eight participants described the quality of their pain as *pressure*. Pressure in common usage is defined as "the application of force to something by something in direct contact with it."<sup>163</sup> Most of these pain descriptions included the word pressure. A 63-year-old Caucasian woman who had surgery for a right temporal mass said, "It feels like a lot of pressure behind my forehead. It feels like a lot of pressure and it's pushing in there or like it's full and it can't get any fuller." Others did not use the word pressure but described a sensation of pressure as being squeezed. A 54-year-old Caucasian woman who had surgery for an oligodendroma said it was like having her head in a vise and having a screw put in. Several of the participants indicated that the pressure was severe;

they described it as “lots and lots of pressure,” “intense pressure pain,” or pressure that “really, really hurts.” The participant quoted above who described the pain as having her head put in a vise also said the pressure “makes you feel like your head will explode.” Most of the participants described the pressure as constant, but one participant experienced it only when she vomited. Some described the pressure throughout their heads but others described it as localized, such as in the forehead or at the site of the incision.

### **Pain as Tender or Sore**

Eight participants described the quality of their pain as *tender* or *sore*. Tender is defined in common usage as “sensitive to touch or palpation,”<sup>164</sup> and sore as “physically tender (as from overuse or injury).”<sup>165</sup> Many of the participants described their pain using the words tender or sore. A 69-year-old Caucasian woman who had surgery for a glioblastoma stated, “When I let my head down, it is a little tender.” Several indicated they only felt pain upon touch. A 48-year-old Caucasian woman who had surgery for a cerebral meningioma said, “Right now I am sore and if I touch it, it hurts.” Others described tenderness due to bruising or swelling. This type of pain was usually described as mild or manageable and occurred occasionally. While the soreness or tenderness was typically at the incision site, it could occur elsewhere as well. An 83-year-old Caucasian man who had surgery for a glioblastoma described several of the common elements of pain as tender or sore:

[The pain is] very minor here right where I had pain before. And I have pain now when I touch it. There’s not much pain here, in fact, it’s less. It’s not throbbing. I have a sore spot which is somewhat like before. I’ve got pain in my brain. Now it’s sore and it’s only sore because I touch it.

### **Pain as Stabbing**

Five participants described the quality of their pain as *sharp* or *stabbing*. Sharp in common usage is defined as “severe or harsh” or “clear in outline or detail,” whereas

stabbing is defined as “a sudden sharp feeling.”<sup>166-167</sup> Most of these participants’ pain descriptions included the word sharp. A 34-year-old African-American woman who had surgery for a glioblastoma said the pain felt like “a very sharp, stiff pain spiking in and out.” A 28-year-old Caucasian man who had surgery for a low-grade glioma described the onset of the pain in this way:

It starts to feel like I’m getting stabbed with needles in the side of my face and my head. If it goes on, I start to [also] get a headache.... It just feels like I’m getting stabbed and then it gets a little tingle. It kind of feels like I’m getting stabbed with a pin and then it almost feels like it’s bleeding.

The timing of the sharp or stabbing pain varied. Some participants said the pain was constant and on-going, whereas one said it was occasional and then went away. The location also varied as some participants said the sharp or stabbing pain was “all over,” whereas one said it was localized to the incision site.

### **Pain as Throbbing**

Four participants described the quality of their pain as *throbbing*. In common usage, throbbing is defined as “pulsating or pounding rhythmically.”<sup>168</sup> All of the participants in this group used the word throbbing to describe their pain. A 21-year-old Caucasian man who had surgery for a schwannoma said when the pain really hurt, it throbbed. A 36-year-old Caucasian woman who had surgery for a metastatic brain tumor described the pain like a heartbeat. All four participants indicated that the throbbing pain was intense. A 34-year-old African-American woman who had surgery for a glioblastoma stated, “It [the pain] was excruciating upon waking up. The pain was a shock to me. I felt like I had taken an axe to the head. It was a throbbing pain all around the incision.” One participant said the throbbing pain occurred upon coughing, and another said the throbbing pain was on-going. Some of these participants said the pain was localized to the site of the incision.

### **Pain as Jarring**

Four participants described the quality of their pain as jarring. In common usage, to jar is defined as “to have a harsh or unpleasant effect on someone or something,” or as “to hit or shake (something) forcefully.”<sup>169</sup> Only one of these four participants used the word jarring to describe the pain. This participant, a 73-year-old Caucasian woman who had surgery for a cerebral meningioma, said, “My head was fine until I coughed the first time and then it just jarred and would hurt so bad.” The others used descriptions that are consistent with the definition of jarring presented above. They discussed feeling like they were slapped, slammed, or hit on the side of the head. A 22-year-old Caucasian man who had surgery for metastatic brain cancer stated, “Imagine those weird curvy bike racks and slamming your head into one of those and it being this incision.” For some the jarring pain occurred following sudden movements such as coughing or bending over.

### **Pain as Itching**

Four participants described the quality of their pain as itching. In common usage, to itch is defined as “to have or produce an unpleasant feeling on your skin or inside your mouth, nose, etc. that makes you want to scratch.”<sup>170</sup> Most of the participants in this category used the word itches when describing the quality of their pain. The 22-year-old man mentioned above said, “At its best, it [his pain] itches.” One participant did not use the word itch but instead described needing to scratch. Although itching might not be considered pain, these participants deemed it so and described it as particularly bothersome and often unremitting. The 73-year-old woman mentioned above described the common elements of *pain as itching*:

My forehead hurts just a little bit and I just wanna get in my head and dig.  
I have all this and it's real heavy and I just wanna get in there and  
[scratch].

### **Pain Descriptions Limited to Severity, Location, and Timing**

All participants did not provide descriptions of the quality of their pain. Despite multiple queries by the interviewer about “what the pain felt like,” some participants only described the intensity, timing, or location of their pain. Descriptions of pain intensity ranged from mild discomfort to severe and excruciating pain. A 50-year-old Caucasian man who had surgery for a glioblastoma described his pain as tolerable. In contrast, a 59-year-old Caucasian woman who had surgery for an acoustic neuroma stated that she was crying because her pain was so horrible. Descriptions of the timing of the pain ranged from intermittent to constant and most participants indicated the pain decreased over time. A 34-year-old Caucasian woman who had surgery for a vestibular schwannoma described her pain as occurring “every now and then,” whereas the 59-year-old woman mentioned above described her pain as constant. While for her the pain lessened over time, she stated, “It’s still there if you don’t take anything.” The participants described the location of their pain mostly as occurring in the same location as the surgery, although for some the pain was generalized throughout their heads.

### **Case Examples of Descriptions of Pain Quality**

While the participants described the quality of their post-craniotomy pain with the six basic types of descriptions discussed above, many portrayed their pain using several of these descriptors. Examining individual cases revealed the multi-faceted nature of the post-craniotomy pain experience. Below we present three participants whose descriptions of their pain were particularly complex or dynamic. We refer to these participants as Participant 1, 2, and 3.

#### **Participant 1**

Participant 1 was a 36-year-old Caucasian woman who had surgery for metastatic brain cancer and had been in the hospital for five days at the time of the interview. She had surgery on the left side of her skull using an anterior approach and



had general anesthesia. After surgery, she had been prescribed various narcotics for post-surgical pain, including hydromorphone, oxycodone, morphine, fentanyl, and oxycodone with acetaminophen. Some of the analgesics were ordered for as frequently as every two hours, while others were to be given once daily. She was also prescribed daily doses of hydrocortisone to control post-surgical swelling. She had several surgeries in her lifetime but described this surgery as one of the most painful.

Participant 1 described the quality of her pain in multiple ways, offering vivid descriptions of it throughout her hospital stay. She initially described her pain in a way that was consistent with what we have labeled as jarring pain. She said,

I didn't realize that I was in pain until I bent over to grab something off the floor, just a wrapper, pick it up, throw it away. Even bending at the knees still hurt, you just squat down and bend, you know, if you got up too quickly that hurts. Obviously, if someone hits you in the head with something, it hurts. Coughing. I coughed last night and I felt like someone took a cinder block and broke it over the top of my head.

She later described the pain in the following way: "It was the same as like there's little tiny men going in there and ripping open your head. And pounding your head with little hammers. It sounds crazy but it hurts."

In another instance, she described her pain as throbbing. She said,

I've laid on the back of my head [which is close to the incision] and it's not a very comfortable feeling. The pain is more of a throbbing. It's like you could feel your heartbeat. And the more you feel your heartbeat, the worse the pain gets.

She described her pain when she walked in yet another way. In this instance, she described a "vibrating" pain that went up her spine and that "kind of hurt."

One of her descriptions combined several of the types of pain quality. She said,

They're [types of pain] all different. They all feel like you could feel your heartbeat, but when I cough really hard, it felt like my head almost split open like the incision, that's what it felt like. It was a hard cough and it threw me for a loop. It hurt from my head down to the middle of my neck, it hurt. So that's pretty painful.

## Participant 2

Participant 2 was a 48-year-old Caucasian woman who had surgery for a cerebral meningioma and had been in the hospital for four days at the time of the interview. She had surgery on the left side of her skull using an anterior approach and had general anesthesia. After surgery, she had been prescribed various narcotics for post-surgical pain, including hydromorphone, fentanyl, and hydrocodone with acetaminophen. Some of the analgesics were ordered for as often as every five minutes, while others were ordered for every four hours. She was also prescribed daily doses of dexamethasone to control post-surgical swelling.

Participant 2 described a pain trajectory that was similar to other participants as she had severe pain immediately after surgery and pain that lessened over time throughout the post-surgical period. When she discussed her pain immediately after surgery, she did not describe the quality of her pain but instead focused on its intensity. She stated,

The first day was a killer. Oh, my, God. The first day of surgery, I was demanding pain medicine every two minutes because it hurt that bad. The pain was extremely excruciating. It was horrible.

Later in the interview, she again stressed the intensity of her pain upon waking from surgery: "On a scale of one to ten, it was a twenty. It was horrid. It would not go away. It was just bad. The first day was bad."

When the interviewer inquired about the quality of her pain right after surgery, Participant 2 likened it to a migraine. She stated,

Migraines run in my family bad and that's what it felt like to me, was having a severe migraine attack. It felt so bad that I felt sick to my stomach like I could throw up. I never did, but that's how I felt, like I could have possibly thrown up. The pain was that bad.

As her recovery progressed, however, her pain began to improve with medication. When she described her pain the day following surgery, she said,

It just started stair stepping down from there. Of course, the next day they kept me on a routine schedule where I didn't have to worry about the pain level.

When the interviewer asked her to describe the quality of this lesser pain, she initially described the intensity and stated that she never rated it more than a two or a three on a scale of ten. She then said,

The pain was just like a small headache. Just a general headache that you'd get through the day, that you might need to take a couple of Tylenols or something to get rid of. Nothing major. Just like a small headache. Just a general headache that you'd get throughout the day. And it mostly hurts on this side that he took the tumor from. I'm tender from where I'm bruised and I'm swollen but I'm not hurting from like a headache or anything.

By the time she was interviewed on the third day after surgery, her pain had decreased and she rated it as a "one on a scale of ten." When describing this pain, she stated,

It's tender, but it's nothing like having the headaches. The headaches were totally different than having the little pain from where it's bruised. So, it is different pain. The headaches were like being hit by a Mack truck.

### **Participant 3**

Participant 3 was a 58-year-old Caucasian woman who had surgery for a meningioma and who had been in the hospital for 4 days at the time of the interview. She had surgery on the right side of her skull using a posterior approach and had general anesthesia. After surgery, she had been prescribed fentanyl and oxycodone with acetaminophen. The oxycodone with acetaminophen was ordered for as frequently as every four hours, while the fentanyl was ordered as a one-time dose. She was also prescribed dexamethasone to control post-surgical swelling.

Participant 3 also described the quality of her pain in multiple ways as it changed over the course of her hospital stay. She initially described her pain in a way that was consistent with what we have labeled as pressure. She said,

It was pretty bad. It was like having the tumor all over again. Because of the pressure and the headache, it was pretty bad.

Similar to the other participants, the quality of her pain changed during the post-surgical period. She described her pain later in a way that is consistent with what we have labeled itching. For her, this kind of pain was more troublesome than the other kinds of pain she experienced. She stated,

The itching and swelling has been the worst. It was really starting to itch and to bother me. I was itching all over from it.

By the third day after her surgery when she was interviewed, her pain had decreased and she described it in a way consistent with what we have labeled tender or sore. She said of the pain at that point,

I don't think I've had much pain, so today has been pretty good except for when I get up to go to the bathroom. It still kind of hurts. I can still feel a little and I wouldn't know if that's because my neck has all swelled back there. It kind of gives the headache a little bit but it's tolerable. It's not like it was... It hasn't been really that bad today.

## Discussion

The majority of the participants reported some pain following their craniotomies. Based on the participants' descriptions, we identified and labeled six types of pain quality: *pain as pressure*, *pain as tender or sore*, *pain as stabbing*, *pain as throbbing*, *pain as jarring*, and *pain as itching*. Many participants gave vivid and complex descriptions of their pain quality, whereas a few gave simple or minimal descriptions and instead focused on the intensity and timing of their pain. Several participants described their pain in ways that varied significantly across the post-surgical period.

While no other studies to our knowledge have provided in-depth descriptions of pain quality in patients who had craniotomies, a few studies did measure the quality of pain following other types of surgery, primarily using the McGill Pain Questionnaire (MPQ).<sup>171-173</sup> In addition to measuring intensity and timing of pain, the MPQ provides sensory, affective, and evaluative word descriptors to capture respondents' subjective

pain experiences.<sup>174-176</sup> Seventy-eight adjectives are divided into 20 groups and respondents are asked to pick the single adjective in each group that best applies to their current pain in response to the question “What does your pain feel like?” For example, from the group labeled “temporal,” respondents would pick from among the following adjectives: flickering, quivering, pulsing, throbbing, beating, or pounding.<sup>174-176</sup> From the group labeled “spatial,” respondents would pick from among the following adjectives: jumping, flashing, or shooting. Each adjective is assigned an intensity point that can be summed for each dimension and for a total cumulative score.<sup>174-176</sup> For example, in a study of pain after surgery for an inguinal hernia, the researchers reported that participants most frequently selected the MPQ pain descriptors of aching, hot or burning, or heavy.<sup>172</sup> In a study of patients following percutaneous transluminal coronary angioplasty, patients with nonspecific pain selected fewer and qualitatively weaker pain descriptors compared to patients with ischemic pain.<sup>171</sup> In a study of patients following breast reconstruction, participants who described sensory pain selected qualitatively stronger descriptors than those that described affective pain.<sup>173</sup>

The pain quality descriptors provided by our participants resonated with several of the adjectives that comprise the MPQ.<sup>174-176</sup> *Pain as pressure*, for example, is analogous to the MPQ descriptors of pressing and crushing; *pain as tender or sore* to the MPQ descriptors of dull, sore, and tender; *pain as stabbing* to the MPQ descriptors of boring, drilling, stabbing, and lancinating; *pain as throbbing* to the MPQ descriptors of pulsing, throbbing, beating, and pounding; *pain as jarring* to the MPQ descriptors of jumping or flashing; and *pain as itching* to the MPQ descriptor of itchy. Several of the groups of adjectives on the MPQ, however, were not mentioned by our participants. For example, our participants did not provide descriptions of pain that were considered sensory pain (e.g., cool, cold, freezing) or tension pain (e.g. tiring, exhausting) on the MPQ.

Although the MPQ,<sup>174-176</sup> which includes a wide variety of pain quality descriptions and allows for quantification of pain quality, has been used to describe post-surgical acute pain in several studies, our study adds to the literature by providing an in-depth description of pain quality in post-craniotomy patients. Using a narrative approach, we were able to capitalize on the unique and vivid descriptions the participants used to describe their pain experience in their own words to provide a rich depiction of the participants' subjective experiences of pain. Such descriptions can add to measures of pain intensity and timing to capture the multi-dimensional nature of post-surgical pain in this population.

### **Limitations**

These findings are best understood in the context of several limitations. The main study limitation was that our interviews were conducted at a single time point. In many cases, this generated robust descriptions of pain quality, including how it changed over time, but in some cases, participants had difficulty articulating the nature of the quality of their pain or identifying how it changed from day to day. We recognize that we likely would have obtained more detailed descriptions of the quality of the participants' pain had we queried them regularly over the post-surgical period. This would have also allowed us to triangulate numerical measures of pain intensity with narrative descriptions of pain quality. Moreover, because our participants were post-surgical patients, all of whom had had anesthesia and most of whom were often taking pain medications, it is possible that their memories of their pain experiences may have been impaired and we may not have fully captured the breadth of possible pain quality descriptions in our interviews.

Because our study was conducted on a single unit at a large urban teaching hospital, it is possible that participants did not experience a full range of pain quality because their pain was managed with a standard protocol. Also, although brain tumors

occur more frequently in non-Hispanic whites than in other minorities,<sup>2</sup> minorities were nonetheless under-represented in our sample. This is problematic because research suggests that different ethnic groups respond to pain differently. Some studies indicate, for example, that Hispanics and African-Americans are more likely to report severe pain than Caucasians,<sup>177,178</sup> Asian Americans are more likely to report less pain or to hide their pain than other groups,<sup>177</sup> and Native Americans have a higher prevalence of pain symptoms compared to the general US population.<sup>177,178</sup>

### **Future Research**

In order to advance our understanding of how pain quality changes over time in this population, we suggest conducting studies at multiple time points after surgery as has been done in studies of pain intensity.<sup>179,180</sup> In addition, conducting interviews at multiple study sites could help generate a broader range of pain quality descriptions that may have been precluded by the routine pain management practices on our single study unit. Moreover, due to differences in how ethnic minorities experience pain quality,<sup>177,178</sup> using a more diverse sample would enable comparison of pain quality descriptors among groups. A larger sample would allow for exploration of the impact that other factors, such as age and type of surgery, might have on the quality of pain. Research that explores associations between pain quality descriptors, numerical pain ratings, and medication doses and frequencies would provide a more comprehensive description of the pain experiences in this population.

### **Clinical Implications**

Despite the limitations of our study, the findings do suggest some clinical implications. Because the descriptions of pain quality in patients' own words provide a different understanding of their post-surgical experiences than do numerical pain ratings, clinicians should engage patients in discussions about their unique pain experiences. Clinicians could initiate these discussions with the following questions: How would you

describe the pain?; How does the pain feel?; or What is the pain like to you? Asking questions such as this will result in a more comprehensive assessment of patients' pain. Providing patients an opportunity to describe the quality of their pain might reveal experiences that are quite bothersome although not necessarily severe, such as itching pain. A better understanding of the quality of pain might also suggest some ways to tailor non-pharmaceutical pain management strategies. *Pain as jarring*, for example, may indicate a need to limit exertion during post-surgical activities such as physical therapy, *pain as pressure* may suggest the need to reduce swelling, and *pain as itching* may call for topical solutions.

## **Conclusion**

Pain quality is a critical dimension of the pain experience but it is not frequently studied. The quality of pain experienced by post-craniotomy patients varies considerably and influences their post-surgical experience in important ways. Our classification of six types of pain quality descriptors in post-craniotomy patients, if further developed and validated, could advance our understanding of the subjective experiences of pain in this population and might possibly provide a foundation for the improvement of pain care for patients who have surgery for tumor removal.



Table 3.1. Demographic and Medical Record Data (n=26)

		n	%
<b>Age</b>	20-29 years	3	11.5
	30-39	3	11.5
	40-49	4	15.4
	50-59	4	15.4
	60-69	8	30.8
	70-79	3	11.5
	80-89	1	3.8
<b>Gender</b>	Female	15	57.7
	Male	11	42.3
<b>Race</b>	Caucasian	25	96.2
	African-American	1	3.8
<b>Tumor type</b>	Glioma/ Glioblastoma/ Oligodendroglioma/ Oligodendroma	8	30.8
	Meningioma	6	23.1
	Schwannoma	5	19.2
	Carcinoma	3	11.5
	Hemangioblastoma	2	7.7
	Ependyoma	1	3.8
	Hamartoma	1	3.8
<b>Tumor grade</b>	I	11	42.3
	II	2	7.7

	III	2	7.7
	IV	3	11.5
	Not stated	8	30.8
<b>Tumor location</b>	Frontal	4	15.2
	Frontotemporal	3	11.5
	Temporal	3	11.5
	Posterior fossa	3	11.5
	Skull base	2	7.7
	Suboccipital	2	7.7
	Cerebellar	2	7.7
	Vestibular	1	3.8
	Supratentorial	1	3.8
	Parieto-occipital	1	3.8
	Parietal	1	3.8
	Not stated	3	11.5
<b>Tumor Hemisphere</b>	Right	15	57.7
	Left	11	42.3
<b>Surgical Approach</b>	Anterior	25	96.2
	Posterior	1	3.8
<b>Type of craniotomy</b>	Sedated	17	65.4
	Awake	9	34.6

<b>Analgesics prescribed<sup>1</sup></b>	Fentanyl	23	88.5
	Hydrocodone- acetaminophen	15	57.7
	Acetaminophen	14	53.8
	Oxycodone- acetaminophen	9	34.6
	Hydromorphone	6	23.1
	Morphine	5	19.2
	Oxycodone	4	15.4
	Ibuprofen	2	7.7
	Lidoderm	1	3.8
	Acetaminophen- codeine	1	3.8
	None	1	3.8
<b>Steroids prescribed</b>	Dexamethasone	22	84.6
	Hydrocortisone	1	3.8
	None	3	11.5
<b>Prior pain history</b>	No	24	92.3
	Yes	2	7.7
<b>Prior opioid use</b>	No	25	96.2
	Yes	1	3.8

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<sup>1</sup> The total number of analgesics prescribed does not add up to 26 because many patients were prescribed more than one medication.

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## **CHAPTER FOUR**

This chapter presents the results of a qualitative descriptive analysis of how persons who have undergone a craniotomy for excision and removal of a brain tumor experience pain management during the post-surgical period.

## Introduction

In 2017 in the United States, approximately 23,800 estimated new cases of brain tumor were diagnosed,<sup>181,182</sup> and most of these persons underwent a craniotomy for tumor removal.<sup>182</sup> Pain during the post-surgical period is a significant clinical concern for some patients who undergo craniotomies. Post-craniotomy pain is caused by the incision of the skin and the retraction and reflection of the muscles of the scalp, which is profusely innervated by large and small diameter nerve fibers.<sup>183,184</sup> Post-craniotomy pain is mainly superficial in origin and likely involves the scalp, muscles, and soft tissue of the head, although manipulation of the dura mater covering the brain can also trigger painful sensations.<sup>185</sup> The nature of the pain experienced by post-craniotomy patients is related to the surgical site, with incisions in the subtemporal or suboccipital region producing higher incidences of pain.<sup>185</sup>

Although the percentage of post-craniotomy patients who experience pain within the first two days after surgery is found to be as high as 60-96% despite the use of analgesics, research suggests that healthcare providers may undertreat this pain as they mistakenly believe that craniotomies are less painful than other types of surgery due to lack of innervation in the brain.<sup>185-187</sup> In addition, prescribers may be reluctant to prescribe opioids for post-craniotomy pain because these medications can cause decreased or altered levels of consciousness, thereby masking important neurological changes, or because they can cause respiratory depression leading to increased intracranial pressure and compromised cerebral circulation.<sup>194</sup> Moreover, nausea and vomiting resulting from analgesic administration can increase blood pressure and contribute to an increased risk of aspiration.<sup>188,189</sup> Effective pain management of post-craniotomy pain may also be compromised because few non-pharmacologic strategies for pain management have been developed and tested in this population.<sup>190,191</sup>



Pain care for craniotomy patients in the post-surgical period typically includes the use of opioids,<sup>185</sup> alpha-2 adrenergic agonists<sup>191</sup> such as dexmedetomidine,<sup>192</sup> and adjuvant pain medications.<sup>193,194</sup> During surgery, the use of scalp nerve blocks may decrease the need for additional analgesia after surgery and increase the time between the end of surgery and post-operative analgesic administration,<sup>195-199</sup> while techniques such as wound infiltration can result in temporary decreases in pain after surgery.<sup>200</sup> The addition of atypical analgesics, such as COX-2 inhibitors, to a post-surgical pain regimen may decrease side effects and increase earlier mobilization, thereby reducing hospital stay and associated costs.<sup>188,201,202</sup>

Untreated or undertreated pain during the post-surgical period can negatively affect a number of health outcomes. First, unabated pain following surgery may cause permanent neurological changes leading to the development of persistent neuropathic pain.<sup>203-214</sup> In addition, uncontrolled pain following a craniotomy may cause agitation and sympathetic stimulation resulting in increased blood pressure and swelling.<sup>191</sup> Moreover, acute post-craniotomy pain in brain tumor patients is associated with greater healthcare burden including longer lengths of stay and higher costs of hospitalization,<sup>191</sup> delayed mobilization,<sup>191</sup> higher rates of disability, and poor perceived quality of life due to increased anxiety and depression.<sup>187,204-206</sup>

Despite calls for the development of better strategies to manage post-craniotomy pain, little is known about patient perspectives on pain care following surgery. Pain care improvement initiatives would be enhanced with a better understanding of the pain management experience as described by post-craniotomy patients in their own words. The purpose of this study was to describe how persons who have undergone a craniotomy for excision and removal of a brain tumor experience pain management during the post-surgical period.

## **Methods**

Qualitative Description (QD) methods, as described by Sandelowski,<sup>207</sup> guided this research. QD is the method of choice when the goal of the research is to summarize the experiences of a group in common, everyday terms. Often semi-structured interviews are used to generate information about participants' experiences.<sup>207</sup> When using QD, researchers use low inference analytic strategies such as standard content analysis to summarize data rather than generating abstract concepts from the data set.<sup>207</sup> The outcome of QD is a straightforward summary of the data presented in such a way that it answers important pragmatic practice questions. Because we aimed to provide a straightforward description of patients' pain management experiences following craniotomy, QD methods were most applicable to this study.

### **Setting**

Data were collected from February 2016 through December 2016 at an urban teaching hospital, where an average of 900 craniotomies for the treatment of brain tumor are performed annually. The neurosurgical practice of the hospital draws patients from throughout the Midwestern United States. The study was conducted on the neurosurgical step-down unit, where patients who have undergone procedures for neurological injuries and illnesses including craniotomies are treated. The neurosurgical step-down unit is a 23-bed unit with an average daily census of 23. Patients transferred to this unit are clinically stable with acute care needs that prevent them from being transferred to a medical-surgical acute care unit. Standard post-operative pain medication order sets, which include a variety of recommended oral and intravenous analgesics, are used on the step-down unit.

## **Inclusion and Exclusion Criteria**

Patients who had a craniotomy for the excision and removal of a brain tumor within the prior two weeks were recruited for the study. Other eligibility criteria including being age 21 years and older and speaking English fluently. Patients who were clinical unstable, actively psychotic, and or who had hearing, speech, or cognitive deficits that would interfere with full study participation were excluded.

## **Recruitment**

Institutional review board approval was obtained from the investigators' university, and a waiver of authorization to use protected health information for study recruitment was obtained from the hospital. During each week of recruitment, the medical records of consecutive patients who had been hospitalized for the treatment of primary brain tumor were reviewed by the clinical nurse specialist (CNS) on the unit to determine eligibility. The CNS generated a list of eligible patients and approached them to obtain their verbal consent to be contacted by the primary investigator (first author) to discuss the study. The primary investigator approached and greeted potential participants, and, using a standard script, described the study, confirmed eligibility, and discussed the study requirements. Written informed consent for the interview and review of medical records was obtained from patients who agreed to participate. Participants were informed that their participation was voluntary and that they could choose to withdraw from the study at any time.

## **Data Collection**

In order to fully describe the sample, the following data were collected from the participants' medical records: (1) length of hospital stay; (2) participant age, gender, body mass index, and race/ ethnic background; (3) tumor type, grade, and location; (4) surgical approach, length of time, and head positioning; (5) documented pain ratings; (6) Glasgow Coma Scale ratings; (7) analgesics prescribed, dosages, and number of doses

administered; (8) steroids prescribed, dosages, and number of doses administered; (9) prior pain history; and (10) prior opioid use.

All interviews were conducted in the participants' hospital rooms by the primary investigator. The interviews included questions about (a) how the participants described their pain since surgery, (b) how they dealt with their pain, and (c) how their healthcare providers managed their pain. The ways in which the patients described the quality of their pain is described elsewhere.<sup>208</sup> For this study, prompts were used to obtain robust descriptions of their pain management experiences. For example, whenever possible, the participants were asked to describe specific interactions with providers related to pain care. The interviews were audio-recorded and transcribed by a professional transcriptionist. A few family members were present for the interviews and, in some instances, their comments were recorded. These comments were redacted from the transcripts as family members had not consented to participate in the study.

### **Data Analysis**

Demographic and medical data were described with frequency counts and percentages. Pain intensity ratings and Glasgow Coma Scale ratings were each summarized and averaged for each inpatient day. For the qualitative analysis, the principal investigator and two senior nurse researchers, one with expertise in qualitative methods and one with expertise in oncology, comprised the analysis team. The data were analyzed in four stages using standard content analytic procedures.<sup>209</sup> First, all team members read through the transcripts several times to obtain a thorough understanding of the participants' overall pain management experiences. Second, the primary investigator highlighted and extracted text units (e.g., phrases, sentences, or stories) related to the participants' pain and pain management experiences. These text units were each given a code, which is a word or short phrase that captured the essence of the data. The other team members verified the codes. Third, the primary investigator

created a case-by-topic table.<sup>210</sup> The cases were presented on the vertical axis and topics of interest related to pain management (e.g., descriptions of pain, actions taking by providers, self-management of pain) were placed on the horizontal axis. Each code was placed in the appropriate cell. The codes in each column were summarized, and through team discussion and consensus, categories were developed. Fourth, a narrative description of the categories in each column was written by the principal investigator and confirmed by the other team members.

## **Results**

### **Demographic and Medical Data**

Twenty-eight patients met criteria and agreed to participate in the study. Because one patient appeared somewhat confused after she provided consent, she was not interviewed and her demographic/medical data were not used. The medical record of another patient who was interviewed could not be located. The findings reported here therefore are based on demographic/medical data from 26 patients (*Table 4.1*) but narrative interview data from 27 patients.

Participants were between the ages of 21 and 83 years. As seen in *Table 4.1*, more women than men participated. Most participants were Caucasian; one participant was African-American. Participants' length of hospital stay were between 3 and 13 days. The majority of participants had no prior pain history or history of opioid use.

The most common tumor types were glioma/ glioblastoma/ oligodendroglioma/ oligodendroma and meningioma. Participants were diagnosed with all grades of tumors, with grade 1 being the most common. The tumor grade of 8 participants was not listed in the medical record. The most common tumor sites were frontal, frontotemporal, temporal, and posterior fossa. The tumors were located equally in the left and right hemispheres. The surgeries lasted between 150 and 984 minutes, and the majority of surgeries used an anterior approach. Most participants underwent a sedated rather than

an awake surgery. The most frequently prescribed analgesics included fentanyl; hydrocodone-acetaminophen; acetaminophen; oxycodone-acetaminophen; and hydromorphone. Most participants were also prescribed dexamethasone.

### **Interviews**

The interviews lasted between 7 and 50 minutes with an average of 30 minutes. Most of the participants were oriented and alert. A few were lethargic or slightly confused but still able to participate in the interview. Some participants provided many details and gave elaborate descriptions of their post-operative pain, whereas others were less forthcoming. Some participants were in pain during the interview, but many reported their pain had mostly subsided. The participants' demeanor during the interview varied; some were tearful, some were irritable, and some were in good spirits. While most participants were willing to describe their pain experiences, a few questioned why discussing their pain was important and expressed some frustration during the interviews.

### **Pain Management Experiences**

The analysis revealed that the participants' pain descriptions varied on two major dimensions: the degree to which pain was a salient concern in the context of their overall recovery during the post-surgical period and the complexity of their pain management experiences.

*Salience of pain.* The role of pain in the context of the participants' overall recovery experience varied considerably among the participants. For some, pain was not a salient concern and, despite the fact that the interviews were focused on pain experiences, these participants did not dwell on discussing their pain and often diverted the interviews to topics that were of more concern to them, such as the overall course of their treatment for their brain tumor or their plans for returning home. Often, these participants described their pain as "no big deal," and indicated it was expected,

tolerable, or manageable. For other participants, however, pain was an important concern in their recovery experience and remained the focus of much of their interviews. In some cases, this was because the participants experienced pain that was particularly intense. These participants described their pain, at least at one time point, as excruciating, debilitating, or unbearable. In other cases, pain was a salient concern because it lasted a long period of time, was not well controlled, or interfered with recovery activities, such as physical therapy or diagnostic testing.

*Complexity of pain management experiences.* The complexity of participants' pain management experiences also varied considerably. Some participants described their pain management experiences as routine, simple, straightforward, and generally effective. These patients typically indicated that their level of pain was assessed, they received pain medication, and experienced relief. Other participants, however, described their pain management experiences as complicated, difficult, or trying. Complex pain management experiences could be related to side effects or complications of pain medications, pain that could not be well managed, conflictual interactions with healthcare providers, or other recovery complications that interfered with pain management.

To describe the participants' pain management experiences, therefore, we determined that participants might be placed in one of four potential groups (*Table 4.2*): 1) pain-as-non-salient, routine pain management; 2) pain-as-non-salient, complex pain management; 3) pain-as-salient, routine pain management; and 4) pain-as-salient, complex pain management. Based on information extracted from their narratives and the descriptions of the two dimensions described above, each participant could readily be placed in a group. As would be expected, no participants were placed in the pain-as-non-salient, complex pain management. Within each of the other three groups, common patterns of pain management experiences were identified, and each pattern was given a

label that best captured how the participants described that pattern. *Table 4.2* presents the patterns that comprised the groups. The groups and the patterns are described below with verbatim quotations from the participants that reflect each pattern.

### **Group 1: Pain-As-Non-Salient, Routine Pain Management**

Twelve participants were placed in Group 1. For participants in this group, pain was not a salient concern in the overall context of their recovery and their pain management experiences were described as routine. Within this group, four patterns of pain management were described. These patterns are labeled as follows: 1) *Simply getting pain pills*; 2) *Conferring with staff*, 3) *Waiting the pain out*, and (4) *Having no pain at all*.

*Simply getting pain pills.* Four participants described a pain management pattern that is best described as *simply getting pain pills*. These participants had minimal pain and described it as discomfort or tenderness. A 77-year-old woman stated that her pain "...wasn't a piercing pain. It was more like a discomfort." Several were surprised at how little pain they had following surgery. This group described their pain management experience as simple and straightforward. Either the staff assessed the participants' pain or the participants asked for pain medication, the staff gave them pain medication, and the participants experienced relief. The same participant stated, "Well, basically,... they [the staff] would ask me, how do you feel? What's your pain level? And I would tell them....And um, they would address that with medication."

The participants in this group also used various self-management strategies to deal with their pain. These strategies included sleeping, remaining still, placing wet washcloths on their foreheads, holding their incisions or surgical sites, and distracting themselves with other activities or thoughts.

*Conferring with staff.* Five participants described a pain management pattern that is best described as *conferring with staff*. These participants also indicated that their pain



was minimal and manageable. A 55-year-old man said, “The pain hasn’t been real terrible, not excruciating, so tolerable...I guess.” The participants in this group did not just receive pain medication routinely, but rather discussed plans for pain management with the staff. In some cases, this involved deciding how much medication to take (e.g. “one pill or two”) or deciding when the best time to take the medication would be. For example, some participants discussed with staff when to take their pain medication so they could participate in therapy or go to sleep. As a result, the participants felt like they had some input into how their pain was managed. A 67-year-old woman stated,

I like the fact that they would let me talk and know if indeed I felt I needed something [for pain] or if I thought I could get through, they treated me as if I was intelligent. [I would say], ‘Let—let’s wait another hour until the meds kick in and then I can maybe sleep through the night.’ Or whatever like that. So when they walked you through like that, I appreciated that.

Some of the participants in this group also listed some self-management strategies that they used to deal with their pain. The strategies included dimming the lights and drawing the curtains, decreasing stimulation, and limiting visits from family and friends.

*Waiting the pain out.* Two participants described a pain management pattern that is best described as *waiting the pain out*. These participants also had minimal pain. One described it as a “brain freeze” and the other as “very minor.” Both of these participants thus just waited for their pain to go away by itself without taking any pain medication to manage the discomfort. A 64-year-old woman stated, “You just wait till it goes away. [You] just go over the hump and that’s it.”

These two participants mentioned some self-management strategies as well. One mentioned attempting to “leave the surgical site alone,” and the other mentioned “working hard” to focus on her breathing.

*Not having pain at all.* One participant, a 67-year-old man, had no pain at all after surgery. He simply stated, “[My] head [doesn’t] hurt.” Pain management thus was not a concern, and accordingly, he did not need any self-management strategies.

## **Group 2: Pain-As-Salient, Routine Pain Management**

Seven participants were placed in Group 2. For participants in this group, pain was a salient concern in the overall context of their recovery and their pain management experiences were described as routine. Within this group, two patterns of pain management were described. These patterns are labeled as follows: 1) *Definitely getting pain pills*; and 2) *Staying on top of the pain*.

*Definitely getting pain pills.* Four participants described a pain management pattern that is best described as *definitely getting pain pills*. These participants had pain that was a concern for them because it was severe or enduring, especially soon after surgery. They described it as bad, severe, or “hurting a lot.” A 29-year-old man said, “The pain [the first day] was extremely excruciating – I can’t say the word. It was horrible.” Their pain management pattern was similar to that of *simply getting pain pills*, but because their pain was more problematic, getting medication was a more pressing concern. A 66-year-old man said, “I definitely took the pain medication.” These participants’ pain management, while more urgent, was nonetheless routine. They reported their pain to the staff, the staff gave them pain medications, and typically the pain subsided. If it did not, more pain medication was given that then did relieve the pain. A 48-year-old woman stated,

As soon as I woke up, it was like, ‘Oh, my, God, I’m in so much pain.’ And they told me how much to rate it. And I said, ‘A 20.’ And she said, ‘Okay.’ She said, ‘We’re gonna give you something for it.’ They didn’t let me sit there long before they took care of the situation and gave me something to take care of it. But yeah, when I first came out of it, it hurt like a mother.

Some of these participants also used self-management strategies to manage the pain. The strategies included using ice packs, practicing yoga and relaxation, meditating, and praying.

*Staying on top of the pain.* Three participants described a pain management pattern that is best described as *staying on top of the pain*. These participants experienced severe pain, particularly in the first several days after surgery, and felt the pain was an obstacle to their recovery. Their pain management experience was marked by preemptive efforts not to let the pain take hold. They were vigilant about keeping the pain at bay because they recognized that it was harder to manage it once it occurred. In some instances, the staff stayed on top of the participants' pain by assessing it regularly. A 23-year-old man stated, "They'd come in three or four times a day [and] would give me Norco or Valium or both depending on what I needed...They were pretty on top of keeping my pain in check, which was nice." In other instances, the participants themselves planned ahead so the pain would not take hold. A 29-year-old man described severe pain that recurred as soon as his pain medication began to wear off. He stated,

So knowing that [the medication] lasts for four hours, four hours and ten or fifteen minutes is important, that way I can let these guys know like I did...because I know she's gonna be busy and that way she can get the pills and so forth ...because I'm one of four or five people that she's taking care of...so I definitely wanted to let her know that I was ready for it.

The participants in this group also used a number of self-management strategies to deal with their pain. The strategies included deep breathing, rubbing or squeezing their heads, positioning themselves for comfort, and using heat or ice packs to dull the pain. Some called upon their faith (e.g., "leaning on Jesus") and attempted to find meaning in their pain. Others held family members' hands or talked to them to help manage the pain.

### **Group 3: Pain-As-Salient, Complex Pain Management**

Eight participants were placed in Group 3. For participants in this group, pain was a salient concern in the overall context of their recovery and their pain management experiences were described as complex. Within this group, two patterns of pain management were described. These patterns are labeled as follows: 1) *Not staying on top of the pain*; and 2) *Having everything done to help me*.

*Not staying on top of the pain.* Five participants described a pain management pattern that is best described as *not staying on top of the pain*. Their pain was particularly intense. A 56-year-old woman, for example, had excruciating pain following surgery. She said, “Oh, yeah, I was crying, shaking, all the nine yards.” In some cases, the pain lasted for most of the recovery period. These participants’ experiences were marked by a sense that staff were not invested in or able to “stay on top of” their pain. A 77-year-old man stated, “They were trying to give me Percocet and that takes about an hour to kick in, and my pain, they had trouble staying on top of it for a while, so they gave me an IV that kicked in right away, and then some Percocet on top of that...”

In several cases, these participants had difficult pain management experiences because a number of factors complicated their pain treatment. These complications included severe nausea and constipation due to the pain medication, coughing that intensified the pain, adverse reactions to a pain medication, and problems managing high blood pressure or blood glucose. A 56-year-old woman who felt that her pain was a major factor interfering with her recovery stated, “I even think the blood pressure and all that can be very related to the pain and my blood sugar has been up and down. I think a lot of it has to do with the pain.”

As a result, these participants described a somewhat complicated pain management regimen that changed frequently. Some were given a combination of intravenous pain medications, a variety of oral pain medications, and steroids. The 56-

year old woman mentioned above stated, “After the morphine it [the pain] got so much better.... But they were able to absolutely get me back on the Fentanyl without it dropping my oxygen even more, and then they’ve been giving Percocet and Vicodin. So that was what kept me pretty much not in pain.”

The pain management experiences of these participants were also marked with some unsatisfying or conflictual interactions with staff. Some participants indicated that the staff did not give them the amount of pain medication they desired. These participants felt they were given either too many or too few pills. Others felt the staff did not give them the pain medication in a timely enough manner to keep the pain at bay. The participants’ pain management experiences were in some instances made worse because they felt the staff was not listening to them or understanding their experiences. A 34-year-old woman, for example, said she would have to repeatedly ask staff for pain medication but was told she was getting the strongest medication possible and she would “just have to wait” to get more. In some cases, the participants were able to negotiate a pain management regimen with staff that they felt was adequate, whereas others had more contentious interactions. A 36-year-old woman said she was “hardheaded” but did not want to get into “a big argument” with the staff. She explained,

They [staff] just asked me how much pain I was in. I gave them a number and they said, ‘What’s a tolerable – manageable pain for you?’ I said, ‘If it’s about a five. I’m good. If it starts to get up to a six, we need to start the fentanyl because after six, it starts to go up really quickly from there, so if I say it’s six, fentanyl time...’ But at one point, it wasn’t. Because I wasn’t getting the fentanyl every hour like I’m supposed to so, it would go back to, ‘Okay. We’ve got to get this every hour on the hour again.’ And so it got to the point where I’d be like, ‘Give me the fentanyl before you start doing your charting because then it will be an hour before you can get back in here because I can’t deal with going through this again.’

Like the other groups, some of these participants attempted to deal with their pain through using various self-management strategies. They used heat and ice packs,

positioned themselves for comfort, and attempted to distract themselves from the pain by talking to others or watching television.

*Having everything done to help me.* Three participants described a pain management pattern that is best described as *having everything done to help me*. These participants also experienced intense pain and had other experiences, such as severe nausea or a low pulse rate, which complicated their pain management regimen. A 60-year-old woman, for example, described how her pain management was complicated because her pulse went very low and staff had to initially withhold her pain medication, resulting in intense pain. The pain management regimens of these participants also included a variety of types of pain medication that were changed throughout the recovery period due to complications.

Unlike the other participants with complex pain management patterns, however, the participants in this group felt the staff were highly invested in managing their pain, frequently checked on them, and were attentive and understanding. The participants had a sense that the staff did “everything in their power” to help manage the participants’ pain. A 61-year-old woman stated,

The nurse was very nice to come in and she said, ‘Well, what can I do for you? Just tell me, what do you want me to do because I’ll do anything I can.’ And that in itself was nice to hear and she was able to get me a medication to calm me down a little bit.

A 54 year-old woman said, “They [the staff] did everything they can to possibly help me.... They have been there for me, ‘What can I do to help you?’.”

This group used many self-management strategies to address their pain and discomfort. These strategies included sleeping, relaxing, lying still, and trying to rest. They also relied on the support of family members coming in to visit to take their mind off of the pain. One said that crying helped manage the pain and another found eating to be helpful.

## Discussion

All the participants but one had some pain following their craniotomies. Their descriptions of their pain experiences varied on two dimensions: the salience of pain in the context of recovery and the complexity of their pain management experiences. Based on these two dimensions, we divided the participants into three groups: (1) pain-as-non-salient, routine pain management, (2) pain-as-salient, routine pain management, and (3) pain-as-salient, complex pain management. Many participants, regardless of how salient their pain was, described a pain management experience that they considered as uneventful or routine. Their pain was managed to their satisfaction and involved primarily being given pain medication in a timely manner and experiencing the pain medication as effective. Other participants described pain management experiences that were more problematic. In some cases, this was because of the severity and nature of their pain, complications from surgery, or side effects of the medication. In a few cases, this was because of problematic interactions with healthcare providers who did not administer medications in a timely manner, listen to the participants' pain-related concerns, or understand their pain experiences.

Our findings were consistent with those of several other studies that examined patients' experiences with pain management while in the hospital. For example, a study by Farooq et al. examined hospitalized post-surgical patients' satisfaction with acute pain management.<sup>211</sup> Just as the participants in our study were generally satisfied with their interactions with staff regarding pain management, these researchers reported that most patients in their study felt their pain was well managed and they were satisfied with their experiences with the hospital staff.<sup>211</sup> However, consistent with our results, a few of the participants in the Farooq et al. study felt that their pain was not well controlled and that their pain medications were administered too late.<sup>211</sup> Our major finding – that the majority of patients had an uneventful course of pain management because they were

given analgesics that managed their pain well – was similar to the finding of a study that revealed that head and neck cancer patients undergoing radiotherapy felt their pain was managed in a timely way.<sup>212</sup>

The experiences of the few of our participants who had problematic interactions with staff related to pain management was echoed in several other studies of hospitalized patients who experienced pain. For example, a study by El-Haddad et al. revealed that patients hospitalized with acute low back pain were unable to communicate the severity of their pain to staff and felt the staff minimized their pain,<sup>213</sup> a study Bernhofer et al. revealed that patients hospitalized with irritable bowel disease reported that they were judged or discredited by staff for experiencing pain,<sup>214</sup> and a study by Coleman et al. revealed that patients with sickle cell anemia reported they felt misunderstood or not believed when reporting their pain levels.<sup>215</sup> While problematic interactions with staff were reported in our sample, none of our participants discussed feeling stigmatized or doubted about their level of pain. This may suggest that the pain management experiences of hospitalized patients with post-surgical pain differ from those with acute pain being treated in the context of chronic pain conditions.

Finally, just as some of participants employed other “self-help” non-pharmaceutical strategies to manage their pain, women in a study by Hovind et al. who had undergone surgery for breast cancer employed their own pain management strategies including physical exercise, relaxation, and distraction.<sup>216</sup>

### **Limitations**

There are several limitations to this study. First, because our participants were hospitalized post-surgical patients who had undergone anesthesia, and most were taking pain medications, it is possible that their memories of their experiences with their pain and/or how it was managed might have been impaired. Some may have had some pain experiences, especially right after surgery, that they could not fully describe, and



this might account, in part, for why some described their overall pain experiences as non-salient. In addition, the use of a single study site and unit may impact our participants' overall level of satisfaction in part due to that unit's pain management practices. Finally, minorities were underrepresented in our sample. While non-Hispanic whites are diagnosed with brain tumors more frequently than other minorities,<sup>182</sup> the experiences of minority patients were not well represented in our study, and we cannot ascertain if they have different pain management experiences.

### **Future Research**

In order to further advance our understanding of the pain management experiences of patients who have undergone a craniotomy, we suggest conducting studies at multiple sites in order to ascertain which pain management experiences might be related to the practices of specific units or institutions. Moreover, obtaining a larger and more diverse sample would allow for exploration of differences in pain management experiences due to demographic factors, such as age or race/ethnicity, and factors related to the type of surgery and the type tumor. To understand how pain management experiences unfold over time, a multi-method study that combines clinician observations, quantitative data such as pain ratings and medication dose, and narratives of patients' subjective experiences throughout the recovery period would be optimal.

### **Clinical Implications**

Despite study limitations, our findings do suggest some clinical implications. Clinicians should be aware that while many post-craniotomy patients experience minor pain and effective and routine pain management, there are others for whom pain management is a trying experience. These patients would benefit from indications that staff are attuned to "staying on top" of their pain and receiving information regarding how their pain will be managed. Pain management best practices, such as regular identification and timely treatment of the side effects and comorbidities that complicate

pain management, administration of pain medications in a timely fashion before the pain “gets out of control,” continual assessment of the effectiveness of the medication regime, and consideration of alternative analgesics when needed, are especially important for these patients. Good patient/provider communication, in which patients feel heard and understood and have input into decisions made regarding their pain management, is foundational to a good pain management experience. Clinicians should also explore with patients what self-management strategies would be acceptable to them and which might enhance their pain management experiences.

## **Conclusion**

The experiences of patients who have undergone a craniotomy vary according to the nature of the pain they experience and their unique experiences of how it is managed. Despite some clinician beliefs that post-craniotomy pain is minimal, our findings confirm that for some patients it is a salient experience that causes distress and interferes with their recovery. Our typology of three distinct types of pain management experiences, if further developed and validated, could advance our understanding of the diversity of pain experiences following craniotomy and the identification of the unique clinical needs of distinct groups of post-craniotomy patients. The study confirms that the nature of patient interactions with clinicians clearly influence patients’ pain care experiences.

Table 4.1. Demographic and Medical Record Data (n=26)

		n	%
<b>Age</b>	20-29 years	3	11.5
	30-39	3	11.5
	40-49	4	15.4
	50-59	4	15.4
	60-69	8	30.8
	70-79	3	11.5
	80-89	1	3.8
<b>Gender</b>	Female	15	57.7
	Male	11	42.3
<b>Race</b>	Caucasian	25	96.2
	African-American	1	3.8
<b>Tumor type</b>	Glioma/ Glioblastoma/ Oligodendroglioma/ Oligodendroma	8	30.8
	Meningioma	6	23.1
	Schwannoma	5	19.2
	Carcinoma	3	11.5
	Hemangioblastoma	2	7.7
	Ependyoma	1	3.8
	Hamartoma	1	3.8
<b>Tumor grade</b>	I	11	42.3
	II	2	7.7

	III	2	7.7
	IV	3	11.5
	Not stated	8	30.8
<b>Tumor location</b>	Frontal	4	15.2
	Frontotemporal	3	11.5
	Temporal	3	11.5
	Posterior fossa	3	11.5
	Skull base	2	7.7
	Suboccipital	2	7.7
	Cerebellar	2	7.7
	Vestibular	1	3.8
	Supratentorial	1	3.8
	Parieto-occipital	1	3.8
	Parietal	1	3.8
	Not stated	3	11.5
<b>Tumor Hemisphere</b>	Right	15	57.7
	Left	11	42.3
<b>Surgical Approach</b>	Anterior	25	96.2
	Posterior	1	3.8
<b>Type of craniotomy</b>	Sedated	17	65.4
	Awake	9	34.6

<b>Analgesics prescribed<sup>1</sup></b>	Fentanyl	23	88.5
	Hydrocodone-acetaminophen	15	57.7
	Acetaminophen	14	53.8
	Oxycodone-acetaminophen	9	34.6
	Hydromorphone	6	23.1
	Morphine	5	19.2
	Oxycodone	4	15.4
	Ibuprofen	2	7.7
	Lidoderm	1	3.8
	Acetaminophen-codeine	1	3.8
	None	1	3.8
<b>Steroids prescribed</b>	Dexamethasone	22	84.6
	Hydrocortisone	1	3.8
	None	3	11.5
<b>Prior pain history</b>	No	24	92.3
	Yes	2	7.7
<b>Prior opioid use</b>	No	25	96.2
	Yes	1	3.8

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<sup>1</sup> The total number of analgesics prescribed does not add up to 26 because many patients were prescribed more than one medication.

Table 4.2. The Four Potential Post-craniotomy Pain Management Groups

	<b>Routine Pain Management</b>	<b>Complex Pain Management</b>
<b>Pain-as-non-salient</b>	<b>Group 1</b> Simply getting pain pills Conferring with staff Waiting the pain out Having no pain at all	
<b>Pain-as-salient</b>	<b>Group 2</b> Definitely getting pain pills Staying on top of the pain	<b>Group 3</b> Not staying on top of the pain Having everything done to help me

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## **CHAPTER FIVE**

### **Summary of Dissertation Project**

Post-craniotomy brain tumor patients often experience pain in the post-surgical period, and this pain can negatively affect their recovery and surgical outcomes. Most research with this population has focused on pharmacological treatments of post-craniotomy pain and has measured only pain intensity. Little is known, therefore, about how these patients experience the quality of their pain and how it is managed while they are hospitalized. The overall goal of this dissertation project is to provide an in-depth description of the experience of post-craniotomy pain during the post-surgical period. The information gained from this project will inform the recognition, treatment, and management of pain in the post-craniotomy brain tumor population.

This dissertation project is composed of two components. The first component is an integrative review of literature examining the evidence of pain and associated symptoms in adult, post-craniotomy brain tumor patients. The second component is a qualitative descriptive study resulting in two qualitative products. The first product is a description of participants' experiences of the quality of their post-craniotomy pain during the post-surgical period, and the second is a description of how they experienced the management of their pain during this time.

### **Three Dissertation Products**

Three products are presented in Chapters 2, 3, and 4 of this dissertation. The findings of each build upon the previous one.

Most studies were randomized, controlled trials conducted outside of the United States that tested the effects of pharmacological pain interventions on pain intensity. This review revealed that between 60% and 96% of post-craniotomy patients experience moderate to severe pain within two days after surgery, and that this pain is associated

with nausea, vomiting, changes in blood pressure, and increased length of hospital stay. These findings contradict the commonly held belief that craniotomies result in little pain and indicate that post-craniotomy pain is a salient experience that affects recovery.

Based on the TOUS,<sup>217,218</sup> and building upon the findings of the integrative review, which reveal that prior research focused only on pain intensity, Product 2 addresses the quality of post-craniotomy pain as described by participants. The findings presented include a description of six types of pain quality: *pain as pressure*, *pain as tender or sore*, *pain as stabbing*, *pain as throbbing*, *pain as jarring*, and *pain as itching*. The findings illustrate that the quality of post-craniotomy pain varies widely and can be described in detail by patients when they are prompted to do so.

The findings of Product 3 build upon the first two products by moving beyond the focus on pharmacological treatments and pain intensity to describe the management of post-craniotomy pain more broadly. These findings reveal that participants' experiences of the management of post-craniotomy pain varied on two major dimensions: the salience of pain and the complexity of the pain management experience. Based on these two dimensions, four groups of types of pain management experiences were identified and labeled as follows: *pain-as-non-salient, routine pain management*; *pain-as-non-salient, complex pain management*; *pain-as-salient, routine pain management*; and *pain-as-salient, complex pain management*. The findings indicate that pain management experiences vary considerably and are influenced by a number of factors, most notably the quality of the participants' interactions with healthcare providers.

### **Synthesis of Key Findings**

Although the findings of the dissertation project are detailed in the three products, several overarching themes were apparent when the findings of all three products were considered as a whole. These three themes are presented below.

**Theme 1: Many post-craniotomy patients experience pain in the post-surgical period, although their pain experiences vary considerably among patients and over time.**

The majority of participants represented in the integrative review and those who participated in the dissertation study experienced pain following their craniotomies. The pain experience, however, varied considerably; some participants experienced pain that was mild and hardly noticeable, whereas others experienced pain that was severe and interfered in important ways with their recovery. Although a few participants in the study had considerable lingering pain at the time of the interview, most indicated that their pain had lessened gradually over the post-surgical period. Post-craniotomy pain is thus a complex and highly individualized experience.

**Theme 2: The quality of the pain that post-craniotomy patients experience is an important dimension of the pain experience.**

The quality of pain is an important but not well explored dimension of the post-craniotomy pain experience. This theme is consistent with the basic tenet of the Theory of Unpleasant Symptoms (TOUS)<sup>217,218</sup> that suggests that symptoms are multi-dimensional experiences that are influenced by a wide variety of factors. Just as the intensity of pain varies considerably in this population, so to does the quality of pain and individuals' responses to it. Understanding the quality as well as the intensity of post-craniotomy pain could have important implications for pain management approaches.

**Theme 3: While the management of post-craniotomy pain often focuses on the administration of analgesics, pain management is a complex process that is influenced by a number of factors.**

Although the participants in the study did indicate that pain medications were the primary way their pain was controlled, they also revealed that their pain management extended beyond receiving analgesics and was influenced by a number of factors such

as nausea and unstable blood pressure, and the quality of interactions with healthcare providers. Patient-provider relationships were important in the pain management experience suggesting that interactions characterized by good communication may improve pain care in this population.

### **Strengths of the Dissertation**

This dissertation project has several strengths and will add to the literature in important ways. First, the integrative review of the literature on post-craniotomy pain is the first review of its kind to be completed in the past 14 years.<sup>219</sup> As such, it contributes to our understanding of the state-of-the-science on pain in post-craniotomy patients. Second, the qualitative descriptive study was the first to examine the quality of post-craniotomy pain, thereby adding to a body of literature that has focused almost exclusively on pain intensity. Third, while much research has examined the efficacy of pharmacological treatment of post-craniotomy pain, this qualitative descriptive study focused on several aspects of pain management as patients experienced it in the context of the patient-provider relationship. Finally, obtaining patient narratives on post-craniotomy pain provided a more nuanced description of this experience from patients' perspectives, thus adding their "voices" to our understanding of this type of pain.

### **Limitations of the Dissertation**

The findings of this dissertation study should be understood in the context of several limitations. First, the interviews were conducted on a single neurological step-down unit. Because the unit utilized a standard pain management order set for all neurosurgical patients, this common order set might have limited the range of ways in which the participants experienced pain. Second, the interviews were conducted at a single time point during the first two weeks after surgery. While providing some robust descriptions of pain quality and pain management, some participants nevertheless had a difficult time remembering and articulating the nature of their pain experiences or how

these experiences changed over time. Third, participants in the study had undergone anesthesia and as a result, it is possible that their memories of the pain experience were imprecise. Fourth, minorities were under-represented in our sample. Research suggests that different minority groups respond to pain in unique ways,<sup>220,221</sup> and because our sample included only two minority participants, group differences could not be examined in this study.

### **Summary of Recommendations for Future Research**

Several recommendations for future studies are based on study findings as well as study limitations. First, conducting studies at multiple sites would allow researchers to distinguish pain experiences that are common to post-craniotomy patients and those that might be site-specific. Second, interviewing participants at multiple time points could result in more detailed descriptions of changes in their pain over the course of the post-surgical period and allow for triangulation of pain narratives with objective data such as pain severity ratings and information about the types, routes, and dose of medication administered. Third, a larger and more diverse sample would allow for exploration of group differences due to demographic factors such as age and minority group as well as factors related to types of surgery and tumor.

### **Practice Implications**

Despite the limitations of this dissertation project, the findings suggest some practice implications for pain care for those experiencing post-craniotomy pain. First, clinicians should reject the commonly held belief that pain is not an important aspect of recovery for the post-craniotomy patient and conduct a comprehensive pain assessment that covers all pain dimensions for each patient. We recommend that clinicians, in addition to obtaining numerical pain ratings, solicit patients' narratives of their pain experiences by asking how the pain feels and what concerns it raises for them. Providing patients with opportunities to discuss their pain experiences could reveal what

patients perceive as particularly bothersome, even if it not severe, such as itching pain. Second, the findings that pain and its management are experienced in such diverse ways indicates that tailored approaches, which may include non-pharmacological strategies and self-management techniques, may be needed to improve patient outcomes. Third, the findings reinforce that best practices, such as “staying on top” of patients’ pain and listening to their concerns, are important. Providers should ensure that pain management occurs in the context of high quality patient-provider interactions.

### **Conclusion**

Pain in the post-craniotomy period for brain tumor patients is a salient, complex, and varied experience. Patient narratives provide an important vehicle for understanding this experience in a comprehensive way. All dimensions of post-craniotomy pain bear further investigation using a variety of approaches in order to develop effective, tailored interventions to enhance patient outcomes. Pain care provided by attuned and attentive providers likely contributes to overall patient satisfaction with post-surgical care.

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## APPENDICES

- A. Inclusion/ Exclusion Criteria
- B. Preliminary Eligibility Screening
- C. Confirmation of Eligibility Script
- D. Indiana University Informed Consent Form
- E. Interview Guide
- F. Demographic and Medical Data Sheet
- G. Research Interview Distress Protocol

## **Appendix A**

### **Inclusion/ Exclusion Criteria**

#### **Inclusion Criteria**

- (1) diagnosed with primary brain tumor and surgically treated with craniotomy,
- (2) 21 years of age or older (can provide independent informed consent); and
- (3) able to speak English fluently (to ensure understanding of informed consent and to enable full study participation).

#### **Exclusion Criteria**

- (1) clinically unstable (including but not limited to presence of post-operative seizures, post-operative intracranial hemorrhage, or altered level of consciousness);
- (2) hearing or speech deficits that would make full study participation impossible;
- (3) active psychosis; and
- (4) other cognitive deficits that would interfere with participants' ability to provide consent and participate in an interview.

## **Appendix B**

### **Preliminary Eligibility Screening**

#### To be obtained from Medical Record:

1. Diagnosis (ensuring patients hospitalized for primary brain tumor)
2. Age (ensuring adults aged 21 years of age or older are only study participants, enabling independent informed consent)
3. Length of stay since craniotomy for the treatment of brain tumor (enabling grouping of data collected)
4. Evidence of clinical instability (including presence of post-operative seizures, post-operative intracranial hemorrhage, or altered level of consciousness)
5. Diagnosis of hearing or speech deficit (to rule out comorbidity that would prevent full study participation)
6. Diagnosis of active psychosis (to rule out comorbidity that would prevent full study participation)
8. Diagnosis of other cognitive deficit (to rule out comorbidities that would prevent full study participation)

## **Appendix C**

### **Confirmation of Eligibility Script**

To be obtained from speaking with potential study participant:

1. My name is Rebecca Guilkey, and I am a doctoral student at Indiana University School of Nursing. I am conducting a research study to describe the post-operative experience of patients who have had a craniotomy for a brain tumor. Is it all right if I ask you a few questions? (verbal consent)
2. Are you able to speak English fluently? (ensuring acquisition of informed consent and study participation)
3. Do you have difficulty hearing? (ruling out hearing impairment that would preclude study participation)
4. Do you have difficulty speaking? (ruling out communicative impairment that would preclude study participation)
5. The study I am conducting will include an approximately 30-minute interview here in your hospital room where, if you were interested in participating, you would tell me your experience of pain on each of the days since you came out of surgery. I am going to use the information to help healthcare providers understand how brain tumor patients experience pain after craniotomy. Understanding what happens from a patient's point of view will help improve recognition and treatment of pain after surgery. Risks of the study are few, but may include discomfort with describing your feelings or the pain you experienced. Are you interested in participating in my study? (If potential participant states, "Yes," the investigator will obtain written consent and interviewing will begin. If potential participant states, "No," investigator will thank patient for his or her time and leave the room.)

## **Appendix D**

# **INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR**

## **THE TRAJECTORY OF ADULT POST-CRANIOTOMY PAIN OVER THE POST-OPERATIVE PERIOD**

You are invited to participate in a research study of patients who have had surgery for the treatment of a brain tumor. You were selected as a possible subject because you had surgery at Methodist Hospital. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Diane Von Ah, PhD, RN, FAAN, Indiana University School of Nursing, Department of Community and Health Systems and Rebecca E. Guilkey, BA, BSN, RN, CCRN, Indiana University School of Nursing, Clinical Nursing Science Doctoral Student. It is funded by Sigma Theta Tau International Nursing Honor Society.

### **STUDY PURPOSE**

The purpose of this study is to understand patients' experiences of pain after brain surgery. This study does NOT involve the use of any investigational (not approved by the Food and Drug Administration) drugs or devices.

### **NUMBER OF PEOPLE TAKING PART IN THE STUDY:**

If you agree to participate, you will be one of approximately 30 subjects who will be participating in this research.

### **PROCEDURES FOR THE STUDY:**

If you agree to be in the study, you will do the following things:

Participate in an interview that should last about 30 minutes. You will be asked to talk about your experience of pain on the days after your surgery. These interviews will be audio recorded. This interview will be done over the course of 1-2 days, depending on your ability to participate. If you agree to be in the study, you will also be agreeing to allow the researcher to look at your medical records to understand how your pain was treated after your surgery.

### **RISKS OF TAKING PART IN THE STUDY:**

While on the study, there is a small risk that you may be made uncomfortable by some of the questions. There is also a small risk of possible loss of confidentiality.

While completing the interview, you can tell the researcher if you want to skip any question or questions with no consequences. You may also tell the researcher if you want to stop the interview or continue at another time with no consequences.

If the researcher believes that you are experiencing emotional difficulty that requires the assistance of your healthcare professional (doctor, nurse), the researcher will end the interview, and with your permission, inform the staff on the unit (doctors, nurses).

Your information, including the audio recordings of your interview, will be kept in secure locked areas and password-protected files that only the researchers can access. Your identifying information (name, contact information) will be removed from the rest of your information and kept in a separate, locked file cabinet.

#### **BENEFITS OF TAKING PART IN THE STUDY:**

One possible benefit to participation might be satisfaction from being able to participate in a study meant to help others with your condition. You will also receive a \$25 gift card upon completion of your interview, whether you answers all of the questions or not.

#### **ALTERNATIVES TO TAKING PART IN THE STUDY:**

Instead of being in the study, you have the option to not participate in the study.

#### **CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and in databases in which the results may be stored. Audio recordings will only be accessible to the researchers and a transcriptionist and will be kept for seven years.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, Sigma Theta Tau International Nursing Honor Society, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP) and the Food and Drug Administration (FDA), the National Cancer Institute (NCI), etc., who may need to access your medical and/or research records.

#### **COSTS**

We do not anticipate any costs to you or your insurance company as a result of your participation in this study.

#### **PAYMENT**

You will receive payment for taking part in this study. Upon completion of the interview, you will receive a \$25 gift card.

#### **COMPENSATION FOR INJURY**

In the event of physical injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

#### **FINANCIAL INTEREST DISCLOSURE**

The researchers have no financial interest in this research and will not benefit financially from this study.

#### **CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study or a research-related injury, contact the researcher Rebecca Guilkey. If you cannot reach the researcher during regular business hours (8:00AM-5:00PM), please call the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949. After business hours, please call your on-call physician.

In the event of an emergency, you may contact Rebecca Guilkey.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

#### **VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University Health Methodist Hospital, Indiana University, or Indiana University School of Nursing. Withdrawing from the study early will not cause a risk to you.

Your participation may be terminated by the investigator without regard to your consent in the following circumstances: if you appear to have emotional distress that requires the treatment of a healthcare provider.

#### **SUBJECT'S CONSENT**

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

**Subject's Printed Name:** \_\_\_\_\_

**Subject's**  
**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

(must be dated by the subject)

**Printed Name of Person Obtaining Consent:** \_\_\_\_\_

**Signature of Person Obtaining Consent:** \_\_\_\_\_ **Date** \_\_\_\_\_

## Appendix E Interview Guide

Participants will be interviewed once and asked to discuss their experiences related to 5 different time points: (1) upon waking up from surgery; (2) the first post-operative day; (3) the second post-operative day; (4) the third post-operative day; and (5) the fourth post-operative day. The interview will proceed according to the following guide:

<b>Post-operative Day 4:</b>						
Thank you for participating in this interview today. I am interested in understanding all I can about your experiences with pain, if any, since you have had any since your surgery. I am interested in how you would describe your pain over these past four days, how you dealt with it, and how your healthcare providers managed your pain. I am interested in knowing whatever you can recall about how you experienced pain. I am going to ask about your pain when you first woke up and during each day since you had surgery.						
	<b>Primary question (Aim 1)</b>	<b>Follow-up questions</b>	<b>Primary question (Aim 2)</b>	<b>Follow-up questions</b>	<b>Primary question (Aim 3)</b>	<b>Follow-up questions</b>
<b>Upon waking up</b>	<i>What was your pain like when you first woke up?</i>	<i>How would you describe your pain when you first woke up? Where did you experience it? How long did it last?</i>	<i>How did you endure or manage the pain when you first woke up?</i>	<i>What strategies did you use to endure or manage your pain when you first woke up? How did these strategies work? What else did you try?</i>	<i>Describe any interactions you had with any of your healthcare providers about your pain when you first woke up?</i>	<i>Who was the healthcare provider (hcp)? How did the interaction begin? (e.g., did the participant request pain relief, was it offered by the hcp?) What happened next? (Applicant will ask about other healthcare providers. If they discuss interactions with physicians, for example, ask about interactions with nurses.)</i>
<b>First Post-</b>	<i>What was your pain like</i>	<i>How would you describe your pain the</i>	<i>How did you endure or manage the</i>	<i>What strategies did you use to</i>	<i>Describe any interactions you had with</i>	<i>Who was the healthcare provider?</i>



<b>operative Day</b>	<i>the rest of that day?</i>	<i>rest of that day? Where did you experience it? How long did it last?</i>	<i>pain the rest of that first day?</i>	<i>endure or manage your pain the rest of that first day? How did these strategies work? What else did you try?</i>	<i>any of your healthcare providers about your pain the rest of that first day.</i>	<i>How did the interaction begin? (e.g., did the participant request pain relief, was it offered by the hcp?) What happened next? (Applicant will ask about other healthcare provider. If they discuss interactions with physicians, for example, ask about interactions with nurses.)</i>
<b>Second Post-operative Day</b>	<i>What was your pain like the second day? (Applicant will provide “anchor” to help patient differentiate post-op days. e.g., Your second day was Tuesday – that was the first day you got out of bed.)</i>	<i>How would you describe your pain the second day? Where did you experience it? How long did it last?</i>	<i>How did you endure or manage the pain the second day?</i>	<i>What strategies did you use to endure or manage your pain when you first got out of bed? How did these strategies work? What else did you try?</i>	<i>Describe any interactions you had with any of your healthcare providers about your pain (here provide anchor; e.g., when you first got out of bed?)</i>	<i>Who was the healthcare provider? How did the interaction begin? (e.g., did the participant request pain relief, was it offered by the hcp?) What happened next? (Applicant will ask about other healthcare providers. If they discuss interactions with physicians, for example, ask about interactions with nurses.)</i>
<b>Third Post-</b>	<i>What was your pain like</i>	<i>How would you describe</i>	<i>How did you endure or</i>	<i>What strategies did</i>	<i>Describe any interactions</i>	<i>Who was the healthcare provider?</i>

<b>operative Day</b>	<i>the third day?</i> (Applicant will provide “anchor” to help patient differentiate post-op days: e.g., <i>Your third day was Wednesday – that was the first day you were allowed to shower.</i> )	<i>your pain the third day?</i> <i>Where did you experience it?</i> <i>How long did it last?</i>	<i>manage the pain the third day?</i>	<i>you use to endure or manage your pain when you first showered?</i> <i>How did these strategies work?</i> <i>What else did you try?</i>	<i>you had with any of your healthcare providers about your pain</i> (here provide anchor; e.g., when you first showered?)	<i>How did the interaction begin?</i> (e.g., did the participant request pain relief, was it offered by the hcp?) <i>What happened next?</i> (Applicant will ask about other healthcare providers. If they discuss interactions with physicians, for example, ask about interactions with nurses.)
<b>Fourth Post-operative Day</b>	<i>What was your pain like the fourth day?</i> (Applicant will provide “anchor” to help patient differentiate post-op days: e.g., <i>Your fourth day was Thursday– that was the first day you were allowed to get dressed.</i> )	<i>How would you describe your pain the fourth day?</i> <i>Where did you experience it?</i> <i>How long did it last?</i>	<i>How did you endure or manage the pain the fourth day?</i>	<i>What strategies did you use to endure or manage your pain when you first got dressed?</i> <i>How did these strategies work?</i> <i>What else did you try?</i>	<i>Describe any interactions you had with any of your healthcare providers about your pain</i> (here provide anchor; e.g., when you first got dressed?)	<i>Who was the healthcare provider?</i> <i>How did the interaction begin?</i> (e.g., did the participant request pain relief, was it offered by the hcp?) <i>What happened next?</i> (Applicant will ask about other healthcare providers. If they discuss interactions with physicians, for example, ask about interactions with nurses.)

**Appendix F**  
**Demographic and Medical Data Sheet**

<b>Page 1</b>		
<b>Hospital Unit (<i>circle one</i>)</b>		
Neurosurgical ICU	Neurosurgical Step-Down	
<b>Length of Stay (in days)</b>	<b>Age</b>	<b>BMI</b>
<b>Gender (<i>circle one</i>)</b>		
Male	Female	
<b>Race (<i>circle one</i>)</b>		
Caucasian	Non-Hispanic White	
African-American	Asian/ Pacific Islander	
Hispanic	Native American	
Decline to state		
<b>Nicotine Usage (Y or N)</b>	<b>Caffeine Usage (Y or N)</b>	
<b>Diagnosis</b>	<b>ICD-9 Code</b>	
<b>Tumor</b>		
<b>Type</b>	<b>Grade</b>	
<b>Location</b>	<b>Hemisphere</b>	
	Proceed to next page →	

<b>Page 2</b>		
<b>Surgery</b>		
<b>Approach</b>	<b>Length of Time (minutes)</b>	
<b>Head Positioning</b>	<b>Type of Craniotomy (<i>circle one</i>)</b>	
	Awake	
	Sedated	
<b>Pain Rating (averaged for each in-patient day)</b>		
<b>Inpatient Day</b>	<b>Pain Ratings</b>	<b>Average</b>
<b>Day 0 (day of surgery)</b>		
<b>Day 1</b>		
<b>Day 2</b>		
<b>Day 3</b>		
<b>Day 4</b>		
<b>Glasgow Coma Scale Rating (GCS; averaged for each in-patient day)</b>		
<b>Inpatient Day</b>	<b>GCS Ratings</b>	<b>Average</b>
<b>Day 0 (day of surgery)</b>		
<b>Day 1</b>		
<b>Day 2</b>		
<b>Day 3</b>		
<b>Day 4</b>		
<b>Medications</b>		
<b>Analgesics Prescribed and Dosages</b>	<b>Frequency</b>	<b>Time Administered</b>
<b>Steroids Prescribed and Dosages</b>	<b>Frequency</b>	<b>Time Administered</b>
<b>Prior Pain History (Y or N)</b>	<b>Prior Opioid Use (Y or N)</b>	

## **Appendix G**

### **Research Interview Distress Protocol**

An adverse event (AE) is defined as any unintended or abnormal reaction or clinical condition that is not of benefit to the participant. Either the response/condition was not present prior to exposure to the study or participation has worsened the intensity or frequency of the response/condition. A reportable adverse event is any unintended or abnormal reaction or clinical condition in a subject that (1) places the subject at increased risk of harm and (2) was unexpected and (3) was related to the research procedures. Extreme fear or anxiety due to study participation may be considered an adverse event in a behavioral/cancer control study. Any breach of patient confidentiality is considered a reportable adverse event.

#### **Expedited Reporting of Adverse Events**

Regardless of study sponsorship, the DSMC chair and/or coordinator will review all expedited SAE reports through OnCore. Expedited reports are completed per IRB guidelines and may include the IRB Prompt Reporting form, non-compliance form, AdEERS reports, Med Watch, and additional SAE forms as required by the sponsor. Submission of this information to the DSMC is additional to any other protocol-specified regulatory bodies (e.g., FDA, pharmaceutical company) to be notified. When follow-up information is received hard copies or electronic versions of NCI AdEERS forms, Med Watch and/or other required forms required by the sponsor should also be provided to the DSMC per the current IRB guidelines. The DSMC chair and/or coordinator will review expedited SAE reports weekly, and report findings to the DSMC quarterly.

#### **Reporting Death**

Report death per local IRB reporting guidelines. (Section 5.8 of the Unanticipated Problems and Noncompliance SOP)

#### **Protocol Deviations**

Protocol deviations are entered into OnCore and reviewed by the DSMC chair and/or coordinator monthly.

## CURRICULUM VITAE

**Rebecca Elizabeth Foust**

### EDUCATION

	Place	Degree	Dates
GRADUATE:	Indiana University Indianapolis, IN	PhD, Clinical Nursing Science	2012 – 2018
UNDERGRADUATE:	Indiana University Indianapolis, IN	Accelerated BSN, Nursing	2004 – 2006
	Butler University, Indianapolis, IN	BA, English <i>cum laude</i>	2000 – 2003
ADDITIONAL:	Central Nine Career Center	Certified Nursing Assistant (CNA)	2004

### ACADEMIC APPOINTMENTS

Place	Title/Rank	Dates
Indiana University Indianapolis, IN	Adjunct Lecturer, Science of Nursing Care Critical Care Clinical	2018 - Present
Indiana University Indianapolis, IN	Adjunct Lecturer, Department of Adult Health Clinical Nursing Capstone	2016 – Present
Indiana University Indianapolis, IN	Adjunct Lecturer, Department of Adult Health Health Coaching/ Behavioral Interventions	2015 – Present
Indiana University Indianapolis, IN	Adjunct Lecturer, Science of Nursing Care Critical Care	2014 – 2015
Indiana University Indianapolis, IN	Adjunct Lecturer, Department of Adult Health Nursing Fundamentals	2012 – 2014
Indiana University Indianapolis, IN	Teaching Assistant, Department of Adult Health Critical Care	2012 – 2013

### CLINICAL APPOINTMENTS

Place	Title/Rank	Dates
Senior Quality Lifestyles Corporation – The Barrington of Carmel Carmel, IN	Nurse Manager – Transitional Nurse	2017 - Present
Kindred Transitional Care and Rehabilitation – SouthPointe, Indianapolis, IN	Director of Staff Development/ Staff Development Coordinator	2016 – Present

St. Francis Hospital, Indianapolis, IN	Staff Nurse/ Charge Nurse/ Rapid Response Nurse, Adult Intensive Care Unit (ICU) Staff Nurse/ Charge Nurse/ Rapid Response Nurse, Adult Step-Down Unit	2007 – 2012
Community Hospital East, Indianapolis, IN	Student Nurse Extern, Renal/ Oncology	2004 – 2006
Greenwood Village Retirement Community, Greenwood, IN	Certified Nursing Assistant, Skilled Nursing Facility	2003 – 2005

#### **LICENSURE**

<b>Type</b>	<b>State/Organization</b>	<b>Dates</b>
Registered Nurse	State of Indiana, United States	2007 – Present

#### **CERTIFICATION**

<b>Type</b>	<b>State/Organization</b>	<b>Dates</b>
Certified Critical Care Nurse (CCRN)	American Association of Critical-Care Nurses	2009 – Present

#### **PROFESSIONAL ORGANIZATIONS**

<b>Organization</b>	<b>Role</b>	<b>Dates</b>
Society of Behavioral Medicine	Member	2015 - Present
Midwest Nursing Research Society	Member	2015 – Present
Graduate Student Nurses' Association	Member	2013 – Present
American Association of Neuroscience Nurses	Member	2012 – Present
American Mensa	Member	2012 – Present
Healthy Work Environment Committee, St. Francis Hospital, Beech Grove, IN	Secretary  Member	2010 – 2012  2009 – 2012
Adult Intensive Care Unit Newsletter, St. Francis Hospital, Beech Grove, IN	Editor-in-Chief	2009 – 2012
CARE Peer Review Committee, St. Francis Hospital, Beech Grove, IN	Peer Reviewer	2009 – 2012

American Nurses' Association	Member	2008 – Present
Sigma Theta Tau, International Nursing Honor Society	Member	2007 – Present
American Association of Critical Care Nurses	Member	2007 – Present
Adult Intensive Care Unit Bereavement Committee, St. Francis Hospital, Beech Grove, IN	Chair	2007 – 2012
Oncology Nursing Society	Member	2006 – 2010
National Student Nurses' Association	Member	2006 – 2009
Greenwood Village South Safety Committee	Member	2005
Sigma Tau Delta, National English Honor Fraternity	Member	2001 – 2003
National Society of Collegiate Scholars	Member	2000 – 2007

### **HONORS AND AWARDS**

Indiana University Elite 50 Graduate Student 2016

Indiana University Faculty Daisy Award 2013

### **GRANTS, FELLOWSHIPS, AND SCHOLARSHIPS**

Sigma Theta Tau International Honor Society of Nursing Research Grant (\$5000) 2015 – 2018

NIH/ NINR T32NR007066 2014 – 2016

Indiana University: Training in Behavioral Nursing (PI: Rawl).  
T32 Scholars Training for the Advancement of Research (STAR)  
Fellow (\$56,000 + tuition and fees)

Jessie Cross Memorial Scholarship, Indiana University (\$1000) 2015

Cheryl A. Bean Scholarship, Indiana University (\$1300) 2014

Nathaniel and Irene Aycock Scholarship, Indiana University (\$3000) 2014

Nathaniel and Irene Aycock Scholarship, Indiana University (\$2500) 2013



Nursing 2000 Graduate Scholarship (\$1000)	2013
Research Incentive Fund (RIF). Indiana University School of Nursing (\$40,000)	2012 – 2016
Jonas Center for Nursing Excellence Leadership Fellow (\$60,000)	2012 – 2014
Sigma Theta Tau New Inductee Scholarship (\$500)	2007

## PUBLICATIONS

\*under previous names\*

1. **Guilkey, R.E.**, Draucker, C.B., Wu, J., Yu, Z., Kroenke, K. (2018). Acceptability of a telecare intervention for persistent musculoskeletal pain. *Journal of Telemedicine and Telecare*, **24**(1), 44-50.
2. **Guilkey, R.**, Von Ah, D., Carpenter, J.S., Stone, C., & Draucker, C.B. (2016) Integrative Review: Post craniotomy Pain in the Brain Tumor Patient. *Journal of Advanced Nursing* **72**(6), 1221-1235.
3. Comer, A.R., Biviji-Sharma, R., Church, A., Gray, W., Grodey, L., **Guilkey, R.**, Harrawood, A., Kirlin, B. & Kunkel, M. (2015). Singapore's breach of its obligations regarding women's health under the United Nations Declarations of Human Rights – Article 25. Hearings of the United Nations Rights Committee, 24<sup>th</sup> Session, January 2016.
4. **Helton, R.** Creating a Healthy Work Environment, *Critical Care Nurse*, October 2009, 78, 80.

## PRESENTATIONS

\*under previous names\*

### International

1. Comer, A.R., Biviji-Sharma, R., Church, A., Gray, W., Grodey, L., **Guilkey, R.**, Harrawood, A., Kirlin, B. & Kunkel, M. (Accepted July 2015). *Singapore's breach of its obligations regarding women's health under the United Nations Declarations of Human Rights – Article 25*. Hearings of the United Nations Rights Committee, 24<sup>th</sup> Session, January 2016, Geneva, Switzerland.
2. **Guilkey, R.**, Von Ah, D., Carpenter, J.S., Stone, C., & Draucker, C.B. (2015, November). Integrative review: *Post-Craniotomy Pain in the Brain Tumor Patient*. Poster presented at the Lawrence S. Bloomberg Faculty of Nursing Quality and Safety Summit – Leveraging Nursing Leadership, Toronto, Ontario, Canada.

### National

1. **Guilkey, R.**, Von Ah, D. (2016, January). Toward a Post-craniotomy Specific Model of Pain. Abstract submitted to the American Society of Pain Management Nurses 26<sup>th</sup> National Conference, Louisville, KY.
2. **Guilkey, R.**, Von Ah, D., Carpenter, J.S., Stone, C., & Draucker, C.B. (2015, April). *Post-Craniotomy Pain in the Brain Tumor Patient: An integrative review*. Poster presented at the 36<sup>th</sup> Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine, San Antonio, TX.
3. **Guilkey, R.** (2013, October). *Working to Implement Nurse Residency Programs*.

Invited paper presentation at the Jonas Center for Nursing Leadership Annual Leadership Conference, Washington, D.C.

### **Regional**

1. **Guilkey, R.**, Storey, S., Tang, C., Nielsen, A., & Von Ah, D. (2015, April). *Pain and Anxiety and Quality of Life in Breast Cancer Survivors*. Poster presented at the 39<sup>th</sup> Annual Midwest Nursing Research Conference, Indianapolis, IN.
2. Tang, C., **Guilkey, R.**, Storey, S., Nielsen, A. & Von Ah, D. (2015, April). *Impact of Depressive Symptoms and Fatigue on Quality of Life in Breast Cancer Survivors*. Poster presented at the 39th Annual Midwest Nursing Research Conference, Indianapolis, IN.
3. Nielsen, A., **Guilkey, R.**, Storey, S., Tang, C., & Von Ah, D. (2015, April). *Physical Activity Level and Symptoms after Diagnosis and Treatment for Breast Cancer*. Poster presented at the 39th Annual Midwest Nursing Research Conference, Indianapolis, IN.

### **Local**

1. **Guilkey, R.**, Von Ah, D., Carpenter, J.S., Stone, C., & Draucker, C.B. (2015, December). Integrative review: *Post-Craniotomy Pain in the Brain Tumor Patient*. Poster presented at the Indiana University Health Nursing Research Conference – Engaging Direct Care Nurses in Research Activities: Creating New Knowledge and Innovative Practices, Indianapolis, IN.
2. **Guilkey, R.**, Von Ah, D., Carpenter, J.S., Stone, C., & Draucker, C.B. (2015, May). *Post-Craniotomy Pain in in the Brain Tumor Patient: An integrative review*. Poster presented at the Indiana University Simon Cancer Center Research Day, Indianapolis, IN.
3. **Guilkey, R.**, Storey, S., Tang, C., Nielsen, A., & Von Ah, D. (2015, May). *Pain and Anxiety and Quality of Life in Breast Cancer Survivors*. Poster presented at the Indiana University Simon Cancer Center Research Day, Indianapolis, IN.
4. **Guilkey, R.** (2015, May). “T32 Update.” PowerPoint presentation at T32 Executive Board and Core Faculty Meeting, Indiana University School of Nursing, Indianapolis, IN.
5. **Guilkey, R.**, Storey, S., Tang, C., Nielsen, A., & Von Ah, D. (2015, April). *Pain and Anxiety and Quality of Life in Breast Cancer Survivors*. Poster presented at the Indiana University Campus Research Day, Indianapolis, IN.
6. **Guilkey, R.** (2014, April). Panel member at Student Professional Development Day, Indiana University School of Nursing, Indianapolis, IN.
7. **Guilkey, R.** (2014, December). “T32 Progress.” PowerPoint presentation at T32 Executive Board and Core Faculty Meeting, Indiana University School of Nursing, Indianapolis, IN.
8. **Guilkey, R.** (2014, May). “T32 Progression.” PowerPoint presentation at T32 Executive Board and Core Faculty Meeting, Indiana University School of Nursing, Indianapolis, IN.
9. **Guilkey, R.** (2014, January). “You are Nursing’s Future: What Legacy Will You Leave?” Podium presentation at BSN New Student Induction Ceremony, Indiana University School of Nursing, Indianapolis, IN.
10. **Guilkey, R.** (2010, March). “Use of Compression Stockings.” PowerPoint presentation at St. Francis Hospital Critical Care, OB/GYN, and Surgical Committee meeting, Beech Grove, IN.
11. **Helton, R.** (2010, March). Panel member at committee meeting with Senator Patricia Miller, Chair of the Indiana Senate Health and Provider Services Committee, St. Francis Hospital, Beech Grove, IN.

**SERVICE**

<b>Organization</b>	<b>Role</b>	<b>Dates</b>
Daughters of the American Revolution, Mary Bryan Chapter, Indianapolis, IN	American History Essay Chair	2017 – Present
	Chapter Cookbook Chair	2017 - Present
<i>Journal of Telemedicine and Telecare</i>	Reviewer	2017 - Present
Junior League of Indianapolis, Indianapolis, IN	Active Member	2017 - Present
	Holiday Mart Mistletoe Madness Committee	2017 – Present
	Winter Provisional	2016 - 2017
<i>Journal of Advanced Nursing</i>	Reviewer	2015 – Present
Cathedral Women's Board, Christ Church Cathedral, Indianapolis, IN	Treasurer	2017 - Present
	Assistant Treasurer	2015 – 2017
	Publicity Chair	2014 – 2015
Breaking the Myths of Nursing Camp, Indiana University School of Nursing, Indianapolis, IN	Volunteer	2013 – Present
Let's Pretend Hospital, St. Francis Hospital, Indianapolis, IN	Volunteer	2010 – 2012
St. Thomas Clinic, Whiteland, IN	Volunteer/ Intake Nurse	2006 – Present